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The Field of Pediatrics

PART I

Chapter 1
Overview of Pediatrics

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Since the late 19th century, pediatrics has been the only discipline dedicated to all aspects of the care and well-being of infants, children, and adolescents, including their health—their physical, mental, social, and psychologic growth and development—and their ability to achieve full potential as adults. The importance of scientific inquiry and research discovery in pediatrics and related subspecialties was cemented by the creation of the National Institute for Child Health and Development (NICHD) in 1962. As the earliest pediatricians focused on social and environmental issues that affected health (e.g., housing, sanitation, and poverty), so too are today's pediatricians (e.g., racism, poverty, and other socioenvironmental influences). In 1959 the United Nations (UN) issued the **Declaration of the Rights of the Child**, articulating the universal presumption that children have fundamental needs and rights. However, the United States is the only UN member that has not yet ratified these rights.

The pediatrician's purpose is to advance the well-being of children, and thus pediatricians must be concerned with specific organ systems, genetics, and biologic processes and also with environmental, psychosocial, cultural, and political influences, all of which affect the health and well-being of children and their families. Pediatricians must be advocates for the individual child, their families, and communities because children cannot advocate wholly for themselves. Pediatricians must serve as advocates of all children irrespective of culture, religion, gender/gender identity, sexual orientation, race or ethnicity, ability, place of birth, or geographic boundaries. The more politically, economically, or socially disenfranchised a population is, the greater the need for advocacy for its children and for those who support children. Youth are often the most vulnerable persons in society, and thus their needs require special attention. As boundaries between nations blur through advances in media, transportation, technology, communication, and economics, a *global*, rather than a national or local, perspective for the field of pediatrics becomes both a reality and a necessity.

The interconnectedness of health issues across the world has achieved widespread recognition in the wake of new and emerging illnesses, such as COVID-19, Zika, Ebola, and severe acute respiratory syndrome (SARS), as well as familiar and persistent illnesses, such as malaria, tuberculosis, HIV/AIDS, and vaccine-preventable illness. Additionally, health issues transcend communicable disease and are influenced by global events, such as war, ethnic wars, mass shootings, bioterrorism, the burning of the Amazon rainforest, and the growing severity of wildfires, storms, drought, and hurricanes brought about by climate change to very specific events, such as the earthquake in Haiti in 2010; the displacement of families during the Syrian refugee crisis in 2016–2018; the White supremacist attack on a mosque in Christchurch, New Zealand, livestreamed in 2019; and George Floyd's and Breonna Taylor's murders in 2020.

VITAL STATISTICS ABOUT CHILDREN'S HEALTH GLOBALLY

From 1990 to 2020, the world population grew at an annual rate of 1% per year, down from 1.3% during the prior 20 years, to reach a population of nearly 8 billion people. The population growth rate continues to decline. The Pew Research Center projects the population to reach 10.9 billion people in 2100 with a growth rate of less than 0.1% at that time because of the fall in fertility rates. Africa is the only continental region that is predicted to continue to have strong population growth, as the 20 countries with the highest birthrates currently are all located in Africa. By 2100, the countries of India, China, and Nigeria are estimated to be the largest. In 2019, the average birthrate in the world was 17.9 births per 1,000 population, with a range from 46/1,000 in Niger to 6.0/1,000 in Monaco. The most populous countries—China (18.5% of the world population), India (17.7%), and the United States (4.3%)—have birthrates of 11, 18, and 11 per 1,000 population, respectively, which were all trending down from previous years. Worldwide, there are roughly 2.5 billion youth under 19 years old, which accounts for approximately one third (32%) of the world's population. The African region boasts the largest share of youth under 15 at 40% compared with 26% globally.

Despite global interconnectedness, the health of children and youth varies widely between and within regions and nations, depending on several interrelated factors. These include (1) economic conditions, (2) educational, social, and cultural considerations, (3) health and social welfare infrastructure, (4) climate and geography, (5) agricultural resources and practices, which account for nutritional resources, (6) stage of industrialization and urbanization, (7) gene frequencies for certain disorders, (8) the ecology of infectious agents and their hosts, (9) social stability, and (10) political focus and stability. Although genetics, biology, and access to affordable and quality healthcare are important determinants, social and structural influences on health outcomes—the physical environment, political and economic conditions, and social, cultural, and behavioral considerations—play as great a role, if not greater.

To ensure that the needs of children and adults worldwide were not obscured by local needs, in 2000 the international community established eight Millennium Development Goals (MDGs) slated to be achieved by 2015. Although all eight MDGs affect child well-being, MDG 4 was exclusively focused on children: to reduce the under-5 mortality rate (U5MR) by two thirds between 1990 and 2015. It was estimated that poor nutrition contributed to more than one third of the deaths worldwide in children <5 years old, so many of the efforts to reach this goal centered on increasing household food security. There has been significant progress toward this goal; the worldwide U5MR decreased by 60% between 1990 and 2021, from 93 deaths per 1,000 live births in 1990 to 38 in 2021. However, the World Health Organization (WHO) cites that between 5.2 and 5.4 million children died worldwide from preventable or treatable causes. Infants younger than 28 days account for over half the deaths, followed by children age 1-11 months, and then by children age 1-4 years old. Children in sub-Saharan Africa are 9 times more likely to die before age 5 than children in the developed areas of the world (see Fig. 3.1). School children (ages 5-9 years old) also experienced a large decline in mortality since the year 1990 related to lower prevalence of infectious diseases.

The infant mortality rate globally (2023) is 27.4 deaths per 1,000 live births, with female infants having a lower rate than male infants. The child death rates in the first year of life were highest in Afghanistan (106.8), Somalia (88.0), and Central African Republic (84.2) per 1,000 live births. In the least developed countries, as classified by the UN, this rate was 45 per 1,000, and the rate was 4 per 1,000 for high-income countries. The causes of infant and under-5 mortality differ greatly between developed and developing nations. The leading causes of under-5 mortality are preterm birth and birth-related asphyxia/trauma, pneumonia, diarrhea, and malaria (Fig. 1.1). As compared with higher-resourced countries, more children less than 5 years old in lower-resourced countries die from non–birth-related causes (see Fig. 3.4).

In developing countries, over half of the deaths in children less than 5 years old resulted from infectious and parasitic diseases, including diarrheal disease (10% of deaths) and pneumonia (15%). Neonatal

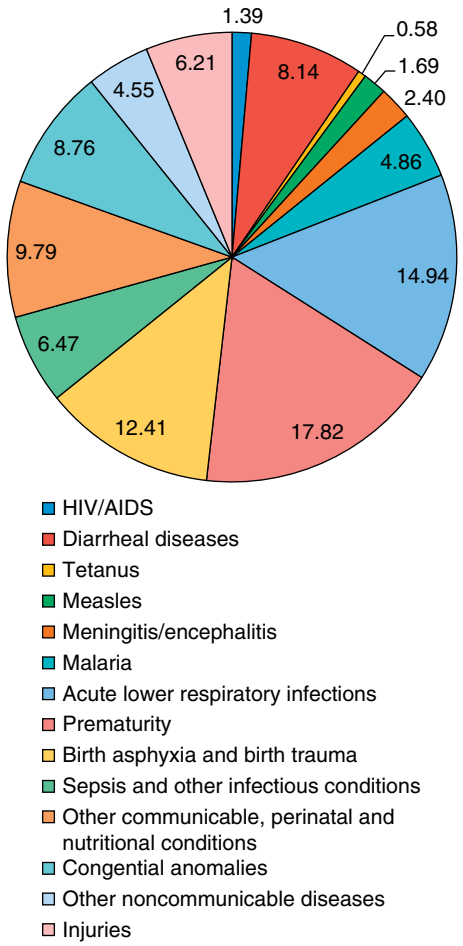

Fig. 1.1 Global causes of death under the age of 5 years.

causes contributed 12%, congenital defects 9%, and malaria, AIDS, and measles accounted for the other causes of death. In the United States, pneumonia and influenza accounted for only 2% of under-5 deaths, with only negligible contributions from diarrheal diseases and malaria (Table 1.1). Although unintentional injuries in developing countries are a proportionately less important cause of mortality than in developed countries, the absolute rates and contributions of these injuries to morbidity are substantially greater. In the United States, the top causes of unintentional injury include unintentional suffocation, drowning, motor vehicle collision, and fire. Other causes accounted for <5% of total mortality within this age-group (Tables 1.2). Violence is a significant contributor to injury-related mortality in all child age-groups (Tables 1.2 and 1.3). Globally (2023), the life expectancy at birth is 73.2 years old, with females at 76 years and males at 70.8 years.

THE CHANGING PEDIATRIC WORLD

A profound improvement in child health within industrialized nations occurred in the 20th century with the introduction of vaccines, antibiotic agents, improved hygienic practices, and attention to scientific clinical practice. Efforts to control infectious diseases were complemented by better understanding of the role of nutrition in preventing illness and maintaining health. In the United States, Canada, and parts of Europe, new and continuing discoveries in these areas led to establishment of publicly funded well-child clinics for low-income families. Although the timing of infectious disease control was uneven around the globe, this focus on control was accompanied by significant decreases in morbidity and mortality in all countries.

Later in the 20th century, with improved control of infectious diseases through more effective prevention and treatment (including the eradication of polio in the Western hemisphere), pediatric medicine in industrialized nations increasingly turned its attention to a broad spectrum of

Table 1.1 Ten Leading Causes of Death by Age Group, United States – 2018

10 leading causes of death by age group, United States – 2018

	Age groups				
Rank	<1	1–4	5–9	10–14	15–24
1	Congenital anomalies 4,473	Unintentional injury 1,226	Unintentional injury 734	Unintentional injury 692	Unintentional injury 12,044
2	Short gestation 3,679	Congenital anomalies 384	Malignant neoplasms 393	Suicide 596	Suicide 6,211
3	Maternal pregnancy comp. 1,358	Homicide 353	Congenital anomalies 201	Malignant neoplasms 450	Homicide 4,607
4	SIDS 1,334	Malignant neoplasms 326	Homicide 121	Congenital anomalies 172	Malignant neoplasms 1,371
5	Unintentional injury 1,168	Influenza and pneumonia 122	Influenza and pneumonia 71	Homicide 168	Heart disease 905
6	Placenta cord membranes 724	Heart disease 115	Chronic lower respiratory disease 68	Heart disease 101	Congenital anomalies 354
7	Bacterial sepsis 579	Perinatal period 62	Heart disease 68	Chronic lower respiratory disease 64	Diabetes mellitus 246
8	Circulatory system disease 428	Septicemia 54	Cerebro-vascular 34	Cerebro-vascular 54	Influenza and pneumonia 200
9	Respiratory distress 390	Chronic lower respiratory disease 50	Septicemia 34	Influenza and pneumonia 51	Chronic lower respiratory disease 165
10	Neonatal hemorrhage 375	Cerebro-vascular 43	Benign neoplasms 19	Benign neoplasms 30	Complicated pregnancy 151

Centers for Disease Control and Prevention
National Center for Injury Prevention and Control

Courtesy Centers for Disease Control and Prevention, https://www.cdc.gov/injury/wisqars/pdf/leading_causes_of_death_by_age_group_2018-508.pdf.

noninfectious acute and chronic conditions. These included potentially lethal conditions in addition to temporarily or permanently disabling conditions. Advances occurred in the diagnosis, care, and treatment of leukemia and other neoplasms, cystic fibrosis, sickle cell disease, diseases of the newborn infant, congenital heart disease, genetic defects, rheumatic diseases, renal diseases, and metabolic and endocrine disorders.

Until the 1970s and early 1980s, children affected with sickle cell disease often died within the first 3 years of life, often from overwhelming sepsis caused by encapsulated bacteria. In the 1980s a multicenter study showed that early initiation of penicillin prophylaxis led to an 84% risk reduction for pneumococcal sepsis. Life expectancy for those with sickle cell disease increased when penicillin prophylaxis was initiated early in life. The use of prophylactic penicillin became the standard of care, increasing the importance of early detection of sickle cell disease (which led to expanding universal newborn screening) and paving the way for advances in the chronic management of the disease, including transfusion therapy, radiographic screening for silent cerebral infarctions, hydroxyurea as a disease-modifying therapy, and now, gene-altering therapies. The success of penicillin prophylaxis likely led to a more rapid rate of innovation in the diagnosis and management of the disease as a result of increased life expectancy. Today 95% of individuals born with sickle cell disease will live to their 18th birthday, and most will survive until their fifth decade.

Similarly, the treatment of acute lymphoblastic leukemia (ALL), the most common pediatric malignancy, has also shown amazing

Table 1.2 Ten Leading Causes of Injury Deaths by Age Group Highlighting Unintentional Injury Deaths, United States – 2018

10 leading causes of injury deaths by age group highlighting unintentional injury deaths, United States – 2018

	Age groups				
Rank	<1	1–4	5–9	10–14	15–24
1	Unintentional suffocation 977	Unintentional drowning 443	Unintentional MV traffic 341	Suicide suffocation 361	Unintentional MV traffic 6,308
2	Homicide unspecified 125	Unintentional MV traffic 292	Unintentional drowning 130	Unintentional MV traffic 360	Unintentional poisoning 4,245
3	Unintentional MV traffic 80	Homicide unspecified 152	Unintentional fire/burn 99	Suicide firearm 202	Homicide firearm 4,107
4	Homicide other spec., classifiable 68	Unintentional fire/burn 123	Homicide firearm 57	Homicide firearm 134	Suicide firearm 2,995
5	Undetermined suffocation 45	Unintentional suffocation 112	Unintentional suffocation 30	Unintentional drowning 86	Suicide suffocation 2,237
6	Unintentional drowning 39	Unintentional pedestrian, other 70	Unintentional other land transport 20	Unintentional fire/burn 52	Suicide poisoning 454
7	Homicide suffocation 30	Homicide other spec., classifiable 66	Homicide unspecified 17	Unintentional suffocation 43	Unintentional drowning 431
8	Undetermined unspecified 30	Homicide firearm 54	Adverse effects 16	Unintentional other land transport 37	Homicide cut/pierce 256
9	Unintentional natural/ environment 22	Unintentional natural/ environment 38	Unintentional pedestrian, other 15	Unintentional poisoning 23	Undetermined poisoning 224
10	Two tied 18	Unintentional firearm 30	Homicide other spec., NEC[N] 14	Suicide poisoning 20	Suicide fall 205

Centers for Disease Control and Prevention
National Center for Injury Prevention and Control

Courtesy Centers for Disease Control and Prevention, https://www.cdc.gov/injury/wisqars/pdf/leading_causes_of_injury_deaths_highlighting_unintentional_2018-508.pdf.

Table 1.3 Ten Leading Causes of Injury Deaths by Age Group Highlighting Violence-Related Injury Deaths, United States – 2018

10 leading causes of injury deaths by age group highlighting violence-related injury deaths, United States – 2018

	Age groups				
Rank	<1	1–4	5–9	10–14	15–24
1	Unintentional suffocation 977	Unintentional drowning 443	Unintentional MV traffic 341	Suicide suffocation 361	Unintentional MV traffic 6,308
2	Homicide unspecified 125	Unintentional MV traffic 292	Unintentional drowning 130	Unintentional MV traffic 360	Unintentional poisoning 4,245
3	Unintentional MV traffic 80	Homicide unspecified 152	Unintentional fire/burn 99	Suicide firearm 202	Homicide firearm 4,107
4	Homicide other spec., classifiable 68	Unintentional fire/burn 123	Homicide firearm 57	Homicide firearm 134	Suicide firearm 2,995
5	Undetermined suffocation 45	Unintentional suffocation 112	Unintentional suffocation 30	Unintentional drowning 86	Suicide suffocation 2,237
6	Unintentional drowning 39	Unintentional pedestrian, other 70	Unintentional other land transport 20	Unintentional fire/burn 52	Suicide poisoning 454
7	Homicide suffocation 30	Homicide other spec., classifiable 66	Homicide unspecified 17	Unintentional suffocation 43	Unintentional drowning 431
8	Undetermined unspecified 30	Homicide firearm 54	Adverse effects 16	Unintentional other land transport 37	Homicide cut/pierce 256
9	Unintentional natural/ environment 22	Unintentional natural/ environment 38	Unintentional pedestrian, other 15	Unintentional poisoning 23	Undetermined poisoning 224
10	Two tied 18	Unintentional firearm 30	Homicide other spec., NEC[N] 14	Suicide poisoning 20	Suicide fall 205

Centers for Disease Control and Prevention
National Center for Injury Prevention and Control

Courtesy Centers for Disease Control and Prevention, https://www.cdc.gov/injury/wisqars/pdf/leading_causes_of_injury_deaths_highlighting_violence_2018-508.pdf.

advances. Five-year survival rates have increased from <10% in the 1960s to >90% in 2023. Cystic fibrosis has shown improvements in survival as well. In the 1960s, most children with cystic fibrosis did not live to school age. With advances in pulmonary and nutritional therapies, as well as earlier initiation of these therapies secondary to earlier identification through newborn screening, a child born with cystic fibrosis in 2010 has a projected life expectancy of 39-56 years.

These major advances in the management of chronic diseases of childhood were accomplished when significant improvement occurred in the prevention and treatment of acute infectious diseases, at least in industrial countries. This allowed human and economic resources to shift toward addressing chronic disease. However, infectious diseases continue to cause significant morbidity and mortality throughout the world. In the fall of 2021, the WHO recommended the use of the RTS,S/AS01 malaria vaccine for children in areas of moderate and high levels of transmission of *Plasmodium falciparum*, which is the most prevalent cause of malaria in Africa. This historic declaration holds great promise for improving children's health, as more than 250,000 African children under 5 die from malaria each year. The coronavirus disease 2019 (COVID-19) pandemic has proved to be an unremitting global health challenge that has not only affected health but also changed and influenced the socioeconomic lives of people throughout the world.

THE NEW NORMAL: PANDEMICS

Since **COVID-19** was first reported and identified in Wuhan, China, in 2019, it has radically and fundamentally affected both the public health and global health landscapes (see Chapters 311 and 449.1). The identification of COVID-19 and development of a vaccine unfolded over the course of 1 year, which was a testament to the importance and critical need for scientific research and rapid clinical implementation. We learned that children could present with or without symptoms and were important factors in community-based viral transmission.

Whereas many children experienced minor illnesses, others experienced more severe illnesses, which were related to underlying chronic conditions, such as asthma or the use of medical devices for children with special healthcare needs, and around 1% of children would go on to develop multiinflammatory syndrome (MIS-C). This condition could be lethal, but most children who received timely care improved. As of spring 2023, there were over 766 million cases and nearly 6.9 million deaths from COVID-19, and the United States had the highest number of cases and deaths throughout the world. Children in the United States accounted for 6 million COVID-19–positive cases, with 0.1–2.0% of children hospitalized and 0.03% leading to child deaths.

Although children were less affected by COVID-19–related illnesses than their adult counterparts, they experienced significant mental health and psychosocial challenges, grief, and loss. Over 1.5 billion

children living through the pandemic faced unprecedented learning challenges because of widespread school closures and dependence on electronic devices and stable internet connections and widening educational disparities, especially for those in poverty, children of frontline workers and single parents, and those already marginalized. Additionally, children who received nutritional support in school or received in-school or in-home services to support their learning and/or developmental needs (e.g., speech therapy, specialized teaching, or other ancillary therapies) also faced disruptions. These disruptions and stress contributed to an increase in mental and emotional health burdens, such as depression, anxiety, isolation, and fear; however, these burdens were unable to be matched with a sufficient number of mental healthcare professionals to provide needed care.

The pandemic also disproportionately affected poor families and families of color in other ways. Children in these families faced increased risk of economic hardship and instability, loss of caregivers, and other challenges. Additionally, concerns about all children's safety and welfare continued and were highlighted, as noncustodial adults had less access and exposure to children who may have experienced physical, sexual, or emotional abuse. Finally, children with special healthcare needs experienced insurmountable challenges throughout the pandemic, such as not receiving essential medicines, medical supplies, and nursing or home healthcare services because of supply chain disruptions and staffing shortages. So although children largely were spared from the illness severity, there were undoubtedly victims of the sequelae that the pandemic brought forth. Now, in partnership with parents, communities, schools, and governments, pediatricians will need to continue to advocate for and support children to mitigate COVID-19's effects on children.

THE NEW MORBIDITIES

Given the advances in public health in decreasing morbidity and mortality in infectious diseases (immunization, hygiene, antibiotics), along with technologic advances in clinical care that improved survival for many chronic illnesses, attention was given to what was described in the 1980s and 1990s as the "new morbidities"—behavioral, developmental, psychosocial conditions, and societal inequities, which have been shown to be increasingly associated with suboptimal health outcomes and quality of life. The prevention, early detection, and management of these types of child health problems should be a central focus of the field of pediatrics and require an expansion in the knowledge base regarding (1) physical and environmental factors affecting behavior, (2) normal child behavior and development, (3) health behaviors as they pertain to child health, and (4) mild, moderate, and severe behavioral and developmental disorders. Accomplishing this would require reconceptualizing professional training, improving clinical communication and interviewing skills, expanding mental health resources for children, and shifting time allocation during child health supervision visits to address these concerns. In 2001 this issue was revisited and reemphasized the need to address environmental and social aspects in addition to developmental and behavioral issues (Table 1.4). This included violence, firearms, substance use, food insecurity, and school problems, as well as poverty, unhoused (homelessness), single-parent families, divorce, social media, incarceration, and childcare. Although at first glance this list seems daunting and beyond the scope of what pediatricians typically address (i.e., physical health and development), many of these behavioral, environmental, and psychosocial problems (which all fall under what was termed the "social determinants of health" but are better characterized as the "**social and structural influences on health**") account for a large proportion of variance in health outcomes in children and youth. The role of pediatrics and the boundaries of clinical practice needed to change in order to address these salient contributors to child health and well-being. Newer models of clinical care that rely on close collaboration and coordination with other professionals committed to child welfare (e.g., social workers, psychologists, mental health providers, educators) were developed. As this model expanded, so did the role of the family, in particular the child's caregiver, from a passive recipient of professional services to a more equitable and inclusive partner in identifying the issues that needed to be addressed, as well as helping decide which therapeutic options had the "best fit" with the child, the family, and the condition.

The framing of salient child health issues under the "new morbidity" concept acknowledges that the influences on health are heterogeneous but interconnected. Biology, genetics, healthcare, behaviors, social conditions, and environmental influences should not be viewed as mutually exclusive determinants; they exert their influences through complex interactions on multiple levels. For example, epigenetic changes that result from specific social and environmental conditions illustrate the influence of context on gene expression.

Studies have demonstrated that while each of these interrelated influences are important for optimal health, development, and well-being, the greatest contributions to health outcomes occur in the behavioral, social, and environmental domains—the social and structural influences on health. From 40% to 70% of the relative variation in certain health outcomes are caused by social and economic conditions, health behaviors, and environmental factors, as well as structural inequality in the healthcare domain. Whereas traditional medical education and clinical practice emphasized the biologic and genetic determinants of health, the recognition of the new morbidities as a focus of child healthcare provision reinforced the need to address social and structural influences as a key component of pediatric care, training, and research.

The "New" New Morbidities

The new morbidities concept brought into perspective the importance of addressing the social determinants of health, as well as the increasing

Table 1.4 A Development History of the New Morbidities in Child Health*

THE NEW MORBIDITIES (1982–1993)	THE NEW MORBIDITIES REVISITED (2001)	THE "NEW "NEW MORBIDITIES (2010 TO PRESENT)
Behavioral disorders/mental health	School problems	Adverse childhood experiences (ACEs)
Family crisis	Mood and anxiety disorders	Toxic stress
Abuse and neglect	Adolescent suicide/homicide	Allostatic load
Long-term disease	Firearms in home	Chronic illnesses of lifestyle (e.g., obesity, type 2 diabetes, hypertension)
Substance abuse	School violence	Behavioral conditions (autism, ADHD, depression, anxiety)
School difficulties	Drug and alcohol abuse	Food insecurity
	HIV	Oral health
	Effects of media	Witnessing community/interpersonal violence
	Poverty	Peer victimization/bullying
	Homelessness	Discrimination
	Single-parent families	
	Effects of divorce	
	Struggle of working parents	
	Child care quality and policy	

*Each column adds further categories and refinements to prior columns.

prevalence and salience of chronic physical and behavioral health conditions in pediatric healthcare. Since then, advances in epidemiology, physiology, and epigenetics have expanded the scope of inquiry into the effects of a broad range of health influences and provided more sophisticated explanatory models for the mechanisms that explain their effects (see Table 1.4).

Racism

Although racism is known as "America's Original Sin," **racism and racial discrimination** is a worldwide problem (see Chapter 2.1). Racism can occur at the systemic/structural, interpersonal, and internal/psychologic levels. Structural racism is the hierarchical grouping of people based on physical attributes, including skin color, which assigns value to those groups and then allocates certain resources, privileges, and power to the dominant or in-group. Structural racism built on White supremacy and hegemony has been a persistent and plaguing problem for over 400 years. It is racism and racist ideology that have created and perpetuated pediatric health disparities by race (see Chapters 2 and 2.1). In the aftermath of the state-sanctioned violence against Black people, there are calls for the end of racism, police actions, and White supremacy ideology throughout the world. The field of pediatrics did not go untouched in these discussions, and numerous articles were presented about how to dismantle structural racism and equip pediatricians with the tools to do so. Importantly, pediatricians have been called to examine areas in which racism and harm are perpetuated through healthcare, through policies, practices, beliefs, and ideals. Racism along with adverse childhood experiences are some of the pressing challenges for the modern-day pediatrician in promoting equitable health access and outcomes.

The issue of racism is even more relevant by understanding that of the ~73,000,000 children in the United States, ~50% are non-White, non-Hispanic (~26% Hispanic, ~14% Black, 5% Asian, ~5% other), 20% speak a language other than English at home, and ~25% are immigrants or children of immigrants.

Adverse Childhood Experiences

Adverse childhood experiences **(ACEs)** are stressful events experienced during childhood that can have profound health consequences both in childhood and throughout the life course into adulthood. ACEs were initially defined as abuse (physical, emotional, sexual), neglect (physical and emotional), and household challenges/family dysfunction (parental spousal abuse, mental illness in household, household substance abuse, incarceration of household member, parental separation or divorce). Retrospective studies have shown a graded dose-response effect of ACEs on future adult health of those who experience the adverse event in childhood. For example, more childhood adversity is associated with significantly increased risk in later life of ischemic heart disease, chronic obstructive pulmonary disease, liver disease, depression, obesity, and cancer. People who suffer ≥6 ACEs die almost 20 years earlier than those who had not experienced ACEs.

Although the original conceptualization of ACEs included family-level psychosocial trauma, recent attempts have been made to expand the concept to include "macro" level stressors, such as those encountered in the neighborhood and community (Table 1.5). These include witnessing violence in the community, poverty, bullying and peer victimization, peer isolation, living in unsafe neighborhoods, low neighborhood social capital, living in foster care, and experiencing discrimination or racism.

ACEs and other psychosocial traumas may influence health through a number of mechanisms. ACEs are associated with adoption of risky behaviors such as substance use and early initiation of sexual activity, which in turn may increase the risk of chronic diseases such as lung cancer, liver disease, obesity, human papillomavirus (HPV) infection and cervical cancer, chronic lung disease, and premature mortality. Childhood trauma can also disrupt neurodevelopment during critical stages of brain development and contribute to social, emotional, and cognitive impairment. Finally, ACEs can result in toxic stress and lead to the dysregulation of normal physiologic processes (see Toxic Stress and Allostatic Load later).

Table 1.5 Adverse Childhood Experiences

CATEGORY	ITEMS
Abuse and neglect	Physical abuse* Physical neglect* Emotional abuse* Emotional neglect* Sexual abuse*
Family dysfunction	Intimate partner violence* Substance use in household* Mental illness in household* Parental separation or divorce* Family member incarcerated* Parental discord
Community-level adversity	Witnessing community violence Neighborhood safety Lack of neighborhood connectedness/trust Experiencing discrimination
Others	Being bullied/peer victimization Living in foster care Social isolation Low socioeconomic status/poverty

*Items included in original Kaiser ACE study.

The documentation of cumulative ACE "scores" has value from a population-based epidemiologic perspective but has *limited clinical utility*. An ACE score gives no information regarding specific adversities and traumas, nor information regarding which interventions may be required. Although ACE screening may not be the optimal approach to incorporating a trauma lens into individual clinical care, a discussion around ACEs can help the clinician to begin collaborative communication with patients and families on the importance of psychosocial stress and adversity in health and well-being in childhood and throughout the life course.

Furthermore, it becomes important to understand that individuals are not merely a sum of their traumas. Although the recognition of the importance of ACEs and **trauma-informed care** has resulted in the reframing of the question "what's wrong with you" to "what's happened to you," this needs to be seen as a transition step toward the goal of **healing-centered care**, which includes an emphasis not only on adversity but also on **assets** (Fig. 1.2). Those assets may be external (e.g., family, community, peers, mentors) or internal (e.g., resilience, positive coping strategies, locus of control). In a healing-centered model of care, the evolution of the question "what's wrong with you" to "what happened to you" gets further refined to include "what's right or positive about you."

Toxic Stress and Allostatic Load

The effects of stress are moderated by the intensity of the stress, the biologic response to the stress, and the social and physical environment in which the stress is experienced. **Toxic stress** occurs when a child experiences stressful events that are chronic, intense, or prolonged and are inadequately buffered by the child's social support system (most importantly, parents and adult caregivers). Toxic psychosocial stress influences physical health by producing allostatic load, or pathophysiologic dysregulation of normal regulatory systems. **Allostatic load** is the "wear and tear" that the body and its regulatory mechanisms experience in response to chronic, unbuffered stress. The systems that can be affected through allostatic load include the neuroendocrine, cardiovascular, immune, and metabolic systems. Dysregulation of stress hormones in the hypothalamic-pituitary-adrenal (HPA) and sympathetic-adrenal-medullary (SAM) systems, inflammatory cytokines, hormones (e.g., insulin), immune factors (e.g., fibrinogen, C-reactive protein), and

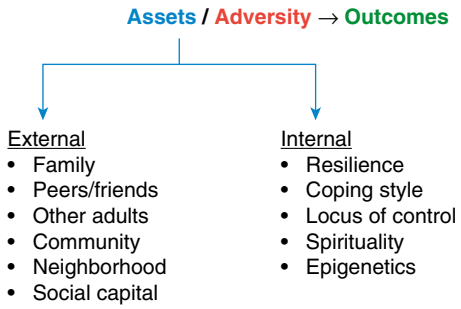

Fig. 1.2 Healing-centered care. Well-being and outcomes are a function of an individual's assets and adversities.

cardiovascular biomarkers (e.g., blood pressure) can occur from chronic stress and result in pathophysiologic conditions associated with chronic diseases. Chronic stress can also have effects at the genetic level. Studies of cellular aging have shown that chronic stress decreases telomere length, a determinant of aging on the cellular level. Epigenetic changes, including differential immune system DNA methylation, may occur after child abuse and posttraumatic stress disorder (PTSD) potentially contributing to inflammatory and immune dysregulation.*

Pediatrics, developmental psychology, basic sciences, and public health have contributed significant advances to the study of the behavioral, developmental, and social influences on child health. The influence of psychosocial stress brought about by environmental challenges, although always acknowledged as important, has taken on a new level of salience as epidemiologists have linked its occurrence to significant morbidities throughout the life course and as basic and clinical neuroscience has provided a multilevel framework for understanding how behavioral and psychosocial issues "get under the skin" to cause physiologic dysfunction and dysregulation. Such a framework can also be seen as a mechanism underlying health disparities (see Chapter 2).

Ecobiodevelopmental Framework

An **ecobiodevelopmental framework** has been proposed to integrate the overlapping influences of environmental (ecologic), biologic, and developmental factors into a model of health and illness. This model posits that ecology (or the social and physical environment) affects biology through physiologic disruptions and adaptations secondary to allostatic load mechanisms. The environment also influences development through life course science, which includes the effects of toxic exposures and childhood adversity on learning, cognitive, behavioral, and physical health throughout the life course. Stress-induced biologic responses to adversity may negatively affect development and biologic health. Biology influences development though brain maturation and neuroplasticity, which in turn are also affected by inputs from the social and physical environment. The ecobiodevelopmental framework is consistent with the biopsychosocial model while adding a longitudinal life course developmental dimension.

CHRONIC ILLNESS AND CHILDREN WITH SPECIAL HEALTHCARE NEEDS

The care of children with chronic conditions has become an increasingly larger part of clinical pediatrics for both the pediatric subspecialist and the general pediatrician. **Children and youth with special healthcare needs (CSHCN)** are defined by the U.S. Maternal and Child Health Bureau as "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally." According to the 2018–2019 National Survey of Children's Health (NSCH), >14.1 million, or 19% of U.S. children, have a special health need. The 2009–2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) reports that almost one quarter (23%) of U.S. households with children have a child with a special need. The conditions these children have are extremely heterogeneous, as shown in Table 1.6. Most of these children need specialty care in addition to primary care. In the United States, 0.4–0.7% of children fall into the category of "highest medical complexity"; these children account for 15–33% of all healthcare spending for children. Children with medical complexity account for >70% of hospital readmissions.

Table 1.6 Children with Special Healthcare Needs (CSHCN)*

HEALTH CONDITIONS
Attention-deficit/hyperactivity disorder
Depression
Anxiety problems
Behavioral or conduct problems
Autism spectrum disorder
Developmental delay
Intellectual disability
Communication disorder
Asthma
Diabetes
Epilepsy or seizure disorder
Migraines or frequent headaches
Head injury, traumatic brain injury
Heart problems, including congenital heart disease
Blood problems, including anemia or sickle cell disease
Cystic fibrosis
Cerebral palsy
Muscular dystrophy
Down syndrome
Arthritis or joint problems
Allergies

*List is not comprehensive and does not include all conditions that CSHCN may have. Adapted from Child and Adolescent Health Measurement Initiative. "2009/10 NS-CSHCN: Health Conditions and Functional Difficulties." Data Resource Center, supported by Cooperative Agreement 1-U59-MC06980-01 from the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA). *Maternal and Child Health Bureau (MCHB)*. 2012. Available at www.childhealthdata.org. Revised 01/27/2012.

Nine of 10 CSHCN have functional difficulties in the sensory, cognitive, movement, emotional, or behavioral domains (Table 1.7). More than 65% (7.2 million) of CSHCN have conditions that affect their daily activities, and >2.3 million families experience financial difficulties because of their children's special health needs. The fact that 25% of family members of CSHCN cut back work hours or stop working because of their child's special needs highlights the social and economic impact of child chronic illness at both the individual and the national economic level.

Pediatricians are typically the "point persons" in the professional care of these children and provide data and expert opinion to procure needed services and resources to the child in the clinic, home, schools, and community. Such demands require an efficient model of chronic care.

SYSTEMS OF CARE

Population Health Approach

Because pediatric practice is increasingly spent working with patients and families who have chronic issues and conditions, new approaches to healthcare services delivery have been proposed. Whereas traditional practice models concentrate efforts toward the preventive and therapeutic needs of those patients who present for care, a **population health approach** to care refocuses efforts to emphasize the need to address health from a community- or population-level perspective, with emphasis on identifying and addressing the needs of individuals and families who do not seek regular care or whose care is episodic and suboptimal from a prevention or management standpoint. Effectiveness of such a system improves with greater collaboration between healthcare providers and payers (insurance companies) to identify gaps in care, with data surveillance systems and **electronic health records (EHRs)** and with an expanded cadre of healthcare personnel such as care coordinators, nurse practitioners, physician assistants, social workers, health navigators, and **community health workers**. Healthcare reimbursement modifications, such as incorporating value-based

Editor Note: Community members and some healthcare workers refer to this disorder as "hood disease."

Table 1.7 Functional Difficulties in Children with Special Healthcare Needs (CSHCN)*

Experiencing difficulty with…
Breathing or respiratory problem
Swallowing, digesting food, or metabolism
Blood circulation
Repeated or chronic physical pain, including headaches
Seeing even when wearing glasses or contact lenses
Hearing even when using a hearing aid or other device
Taking care of self, such as eating, dressing, or bathing
Coordination or moving around
Using his or her hands
Learning, understanding, or paying attention
Speaking, communicating, or being understood
Feeling anxious or depressed
Behavior problems such as acting out, fighting, bullying, or arguing
Making and keeping friends

*List is not comprehensive and does not include all functional difficulties that CSHCN may have.

From Child and Adolescent Health Measurement Initiative. "2009/10 NS-CSHCN: Health Conditions and Functional Difficulties." Data Resource Center, supported by Cooperative Agreement 1-U59-MC06980-01 from the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), *Maternal and Child Health Bureau (MCHB)*. 2012. Available at www.childhealthdata.org. Revised 01/27/2012.

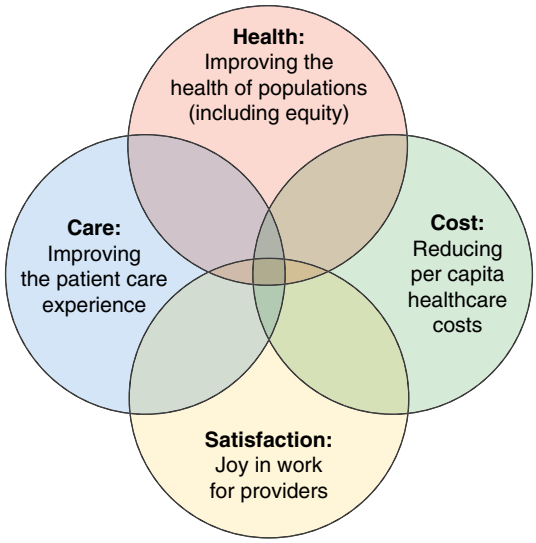

Fig. 1.3 The quadruple aim for healthcare. (*Data from Bodenheimer T, Sinsky C. From triple to quadruple aim: care of the patient requires care of the provider. Ann Fam Med. 2014;12:573–576.*)

and quality-of-care–based models, if implemented correctly, may further advance a population health approach to care.

Medical Home

The concept of the **patient and family–centered medical home** (PFCMH) approach to providing care is defined as a medical home that provides care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. Patients and family members are key active participants, working with clinicians to identify priorities for and approaches to care (**shared decision-making**; see Chapter 18). A key aspect of the PFCMH is **care coordination**. Care coordination "addresses interrelated medical, social, developmental, behavioral, educational and financial needs to achieve optimal health and wellness outcomes." A care coordinator is the "point person" on the team who prospectively identifies the patient's and family's needs, concerns, and priorities for the healthcare visit, gathers pertinent information (lab results, consultations, educational plans, screening/testing results), communicates with subspecialists, and relays all important information to the clinical team before the patient/family visit. After a healthcare visit, the care coordinator works with the family to address any ongoing concerns, directs efforts to schedule follow-up appointments and referrals, and communicates information to all necessary parties. The care coordinator typically is not a physician. The intended result of care coordination is an efficient and comprehensive interaction between the pediatric team and the family, between primary care and specialty care, between ambulatory and inpatient care teams, and between the pediatric care team and the community-based supports on which the patient and family depend.

Provision of care consistent with the elements of a medical home has been associated with more accurate and early diagnosis, fewer emergency department visits and inpatient hospitalizations, lower costs, fewer unmet needs, lower out-of-pocket medical costs, less impact on parental employment, fewer school absences, and better patient satisfaction. According to the 2016 NSCH, 43% of U.S. CSHCN and 50% of U.S. children without a SHCN received coordinated, comprehensive care within a medical home.

Medical and Health Neighborhood

Although the medical home concept relates to practice transformation specific to primary care, a broadening of this concept has been proposed along two separate dimensions. The **medical neighborhood** expands the medical home concept and refers to coordinated and efficient integration between primary care pediatricians and the subspecialists, including integrated EHRs, efficient coordinated appointment scheduling, and enhanced communication. Such a system has the potential to provide a less stressful patient and family experience and could also lead to cost reduction and a decrease in medical errors.

Another expansion and modification of the medical home is the **health neighborhood** concept. The health neighborhood is based on the recognition of the importance of coordination with community-based and nonmedical providers to address comprehensively and efficiently the social and structural influences on health. Health neighborhoods include the healthcare providers (consistent with the medical home and neighborhood) but also involve services such as early intervention programs, the education system, childcare, community-based behavioral and mental health services, legal services, nutritional support services, and other clinical and community-based services that the patient and family need to access. The health neighborhood team helps families identify the needs of the patient, assists with referrals to appropriate agencies outside the healthcare system, and coordinates care.

Some nonmedical services may be co-located at the medical office. **Medical-legal partnerships** (MLPs) are collaborations between the healthcare and legal systems and embed legal aid personnel in the medical clinic. These lawyers and legal paraprofessionals can provide direct services to patients and families who have legal issues that may be affecting the child's health (e.g., housing code violations, utility shutoff, food insecurity, immigration issues, educational accommodations, guardianship). In addition to providing direct services, MLPs train healthcare personnel in the legal, social, and structural influences on health and work with physicians and others to advocate for policy change. Other nonmedical health neighborhood services that could be co-located in the medical center include supplemental nutrition assistance programs, parenting programs, behavioral health services, and family financial counseling.

Many, if not most, other services are located in the community. The health neighborhood model links families to these services and provides efficient ongoing coordination and communication. Community health workers or health navigators are paraprofessional team members who are community and culturally informed and serve as a coordinating link between the family, the medical home, and needed community services. Community health workers and health navigators can also provide patient and family education.

Expanded care models such as these have the potential to achieve what the Institute for Healthcare Improvement calls the "**quadruple aim**" for healthcare: focusing on **care** (improving the patient experience with healthcare, quality care, and satisfaction), **health** (improving the health of populations, including emphasis on equity), provider **satisfaction** ("joy in work"), and **cost** (reducing per-capita healthcare costs) (Fig. 1.3).

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Chapter 2

Child Health Disparities

Lee M. Pachter and Adiaha I.A.Spinks-Franklin

Health and illness are not distributed equally among all members in most societies. Differences exist in historical roots, risk factors, prevalence and incidence, manifestations, severity, and outcome of health conditions, as well as in the availability and quality of healthcare. When these differences are modifiable and avoidable, they are referred to as **disparities** or **inequities**. The U.S. Department of Health and Human Services (DHHS) *Healthy People 2030* report defines *health disparity* as "a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion." The U.S. Centers for Disease Control and Prevention (CDC) define *health disparities* as "preventable differences in the burden of disease, injury, violence, or in opportunities to achieve optimal health experienced by socially disadvantaged racial, ethnic, and other population groups, and communities." Healthy People 2030 defines health equity as "the attainment of the highest level of health for all people. Achieving health equity requires valuing everyone equally with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and health care disparities." Health and healthcare disparities occur because of unequal distribution of resources that are inherent in societies that exhibit *social stratification,* which occurs in social systems that rank and categorize people into a hierarchy of unequal status and power.

ROOT HISTORICAL CAUSES OF STRUCTURAL DETERMINANTS OF HEALTH AND HEALTH DISPARITIES

Figure 2.1 displays a categorization of the multiple determinants of health and well-being. Applying this categorization to health disparities, conceptualizations of the root causes of health disparities emphasize the most modifiable determinants of health: the physical and social environment, psychology and health behaviors, socioeconomic position and status, and access to and quality of healthcare (and the policies that place marginalized groups at greater risk based on these determinants). Differential access to these resources results in differences in *material* resources (e.g., money, education, healthcare) or *psychosocial* factors (e.g., locus of control, adaptive or risky behaviors, stress, social connectedness) that may contribute to differences in health status. This section will explore several historical social and structural root contributors to health disparities (see also Chapter 2.1).

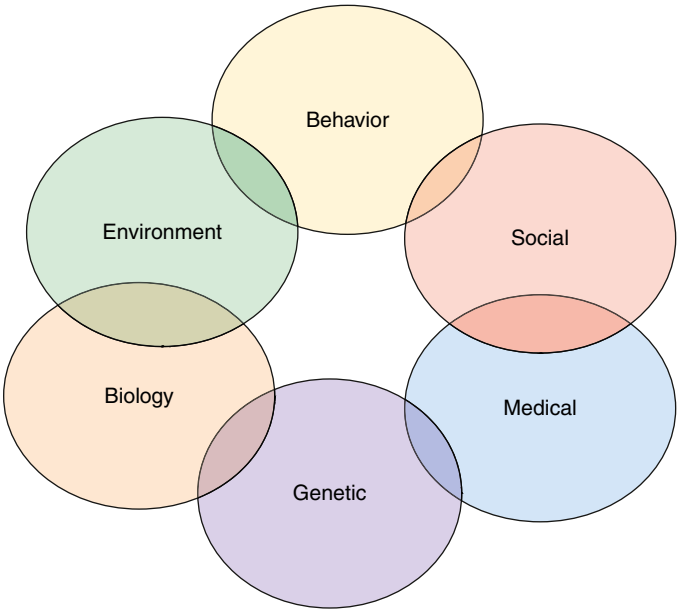

Fig. 2.1 Determinants of health.

Federal Policies and Economic Outcomes

Redlining (1933–1960)

A federally backed homeowner mortgage banking system, the Homeowners Loan Corporation (HOLC), was created in the 1930s and graded neighborhoods on credit risk for investment and mortgage lending into four color-coded levels that were outlined on city maps. The four color-coded levels were based primarily on racial and ethnic demographics rather than economic factors, with the 2 most desirable codes being for more affluent White neighborhoods. Neighborhoods defined as "Definitely Declining" were marked in yellow and were older neighborhoods with mixed ethnic makeup, including lower-income White residents and European immigrant residents, but no Black residents. Residents in these communities were allowed to get homeowner mortgages, but there was less overall economic development. Neighborhoods defined as "Hazardous" were marked in red (hence the term *redlined communities*) and were where Blacks lived, including affluent Blacks. Residents in these neighborhoods were denied homeowner mortgages and were systematically disinvested by local, state, and federal government policies.

The Federal Housing Authority (FHA), created in 1934 to be the government entity that would federally secure homeowner mortgages, created underwriting manuals for banks with rules regarding lending practices that included denying loans to Black applicants and devaluating properties in redlined neighborhoods. Therefore from the 1930s to 1960s, 98% of FHA homeowner mortgage loans were given to White Americans. This led to decades of residential housing segregation. Redlining was officially outlawed by the Fair Housing Act of 1968; however, the impact of redlining continues.

Urban Renewal (1949–1974)

After World War II, city officials and city planners across the United States described urban areas as "slums," full of poor people and in blight. At the same time, the Great Migration (1916–1970) changed the racial makeup for northern cities, when millions of rural southern Black farm workers, domestic workers, laborers, and their families left the harsh Jim Crow segregated conditions of the South and migrated to northern cities seeking a better life and improved economic conditions and opportunities. The leaders in northern destination cities sought to control and contain these southern Black Americans. The federal government passed the Housing Act of 1949 to provide funding to cities across the country to clear and redevelop the slums (called "slum clearance"). City leaders and planners used the funds to revitalize their downtown areas to woo suburban Whites for shopping and entertainment and simultaneously target redlined communities to demolish old buildings and houses and move poor Black and brown residents into public housing facilities (called "housing projects"). In 1956, the Eisenhower administration passed the Federal-Aid Highway Act of 1956 that created the national interstate system. Redlined communities were targeted for placement of these interstate highways that displaced Black and brown residents into segregated housing projects. All of these federal policies led to the following consequences affecting public health:

- **Residential housing segregation**: Fifty-plus years of discriminatory homeowner lending practices, real estate practices, and economic disinvestment have led to *hypersegregation* of neighborhoods and resources. Black and Latinx residents are more likely to live in neighborhoods where the majority of residents have incomes below the federal poverty level, which is referred to as *concentrated poverty.* Residents living in formerly redlined neighborhoods have poorer

health outcomes, including higher rates of asthma, cancer, heart disease, and premature birth and shorter life expectancies. They are at higher risk of being exposed to environmental toxins, including lead, mold, exhaust pollutants and greenhouse gases, that all contribute to poor health. Residential housing segregation has other significant health consequences for Black and Latinx American children, including living in food deserts (having few grocery stores in neighborhoods), digital deserts (lack of access to reliable high-speed internet), having fewer green spaces, and few pharmacies.

- **Economic disparities, racial wealth gap, and concentrated poverty**: Federal policies during the 1930s and 1940s created the foundation for racial wealth gaps. The Social Security Administration and the Servicemen's Readjustment Act of 1944 (the GI Bill) were established to create a middle class. The Social Security system was created to provide income to older adults. However, farmworkers and domestic workers were not included among the professionals that would pay into the Social Security system. *These occupations employed predominantly Black laborers, who did not benefit from the initial Social Security policy.* The GI Bill provided former World War II military soldiers with low-interest home, farm, and business loans; funds to pay for higher education; and unemployment assistance. White and Japanese American soldiers were granted the financial benefits from the GI Bill to buy homes and attend college. However, millions of Black soldiers were denied the GI Bill. First American (i.e., Indigenous Nations peoples) WWII veterans used the GI Bill to pay for a college education, but could not use the GI Bill to buy homes on reservations because reservation land was excluded from the GI Bill. Mexican American soldiers did not have full access to the benefits of the GI Bill for homeownership, but some were able to benefit from job training. Therefore millions of Black, Indigenous Nations peoples, and Mexican American WWII veterans did not receive all the financial and educational benefits of the GI Bill. White Americans have accumulated 10 times the wealth of Black Americans, which has transgenerational implications. Discriminatory hiring and firing practices place minoritized workers at higher risk of chronic underemployment and unemployment. Additionally, there is an ongoing racial and gendered racial pay gap between White American men and women and men and women who are Black, Asian American, Latinx American, and Indigenous Nations peoples. In 2021, for every dollar a White American man made, Asian American women made 85 cents, Black women made 63 cents, Indigenous Nations women made 60 cents, and Latina American women made 57 cents.
- **School segregation and educational underfunding**: Public schools are funded by property taxes. In hypersegregated communities with concentrated poverty, schools are underfunded, with a 2019 study reporting a $23 billion funding gap between school districts with predominantly White students and school districts with predominantly Black, Latinx, and Indigenous Nations students. This funding gap leads to schools with less qualified teachers, less rigorous curricula, and fewer extracurricular activities. Black, Latinx, and Indigenous Nations students have overpolicing and harsher school punishment practices, as discussed further in Chapter 2.1. Schools are not teaching BIPOC students self-discipline; they are overpunishing and criminalizing these students.
- **Environmental injustice**: There are racial disparities in who suffers the health consequences of climate change. Residential housing segregation and environmental policies have contributed to unequal exposure to environmental toxins. White Americans produce the majority of greenhouse gas emissions but experience less of the negative health effects of such emissions such as asthma, other chronic lung disease, cancer, and cardiovascular disease. Black and Latinx American children in hypersegregated neighborhoods are also more likely to be exposed to lead poisoning compared with their White American counterparts. Lead exposure increases the risk of health problems, including anemia, attention regulation problems, and learning problems. Increased exposure to mold and other major asthma triggers contributes to disparities in asthma outcomes among children of color and poor children. Residential housing segregation also places communities of color at risk for poor water quality and the health consequences.

Figure 2.2 illustrates the complex relations among multileveled factors and health outcomes. Historical **social stratification** factors, such as socioeconomic status (SES), race, and gender, have profound influences on environmental resources available to individuals and groups, including neighborhood factors (e.g., safety, environmental toxins, grocery stores, transportation, healthy spaces), social connectedness and support, work opportunities, and family environment. Much of the differential access to these resources results from historical discrimination on a systematic, institutional, and interpersonal level (see Chapter 2.1). Discriminatory policies place historically subordinated groups at greater risk of poorer health outcomes and psychologic functioning, including sense of control over one's life, expectations, resiliency, negative affect, and perceptions of and response to discrimination. Environmental and psychologic context then have influence over more proximal determinants of health, including health-promoting or risk-promoting behaviors; access to and quality of healthcare and health education; exposure to pathogens, toxins, and carcinogens; pathophysiologic responses to stress; and the resources available to support optimal child development.

Psychosocial Stress and Allostatic Load

An understanding of allostatic load helps explain how psychosocial stress influences disease, health outcomes, and health disparities (Fig. 2.3 and Chapter 1). *Allostasis* refers to the normal physiologic changes that occur when individuals experience a stressful event, including activation of the stress-response systems, changes in levels of inflammatory and immune mediators, cardiovascular reactivity, and metabolic and hormone activation. These are normal and adaptive responses to

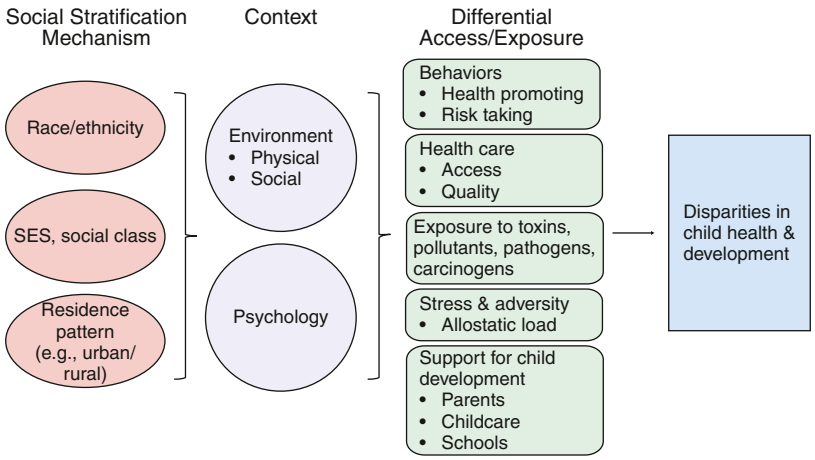

Fig. 2.2 Child health disparities. SES, Socioeconomic status. (*Data from Adler NE, Stewart J. Health disparities across the lifespan: Meaning, methods, and mechanisms. Ann NY Acad Sci. 2010;1186[1]:5–23.*)

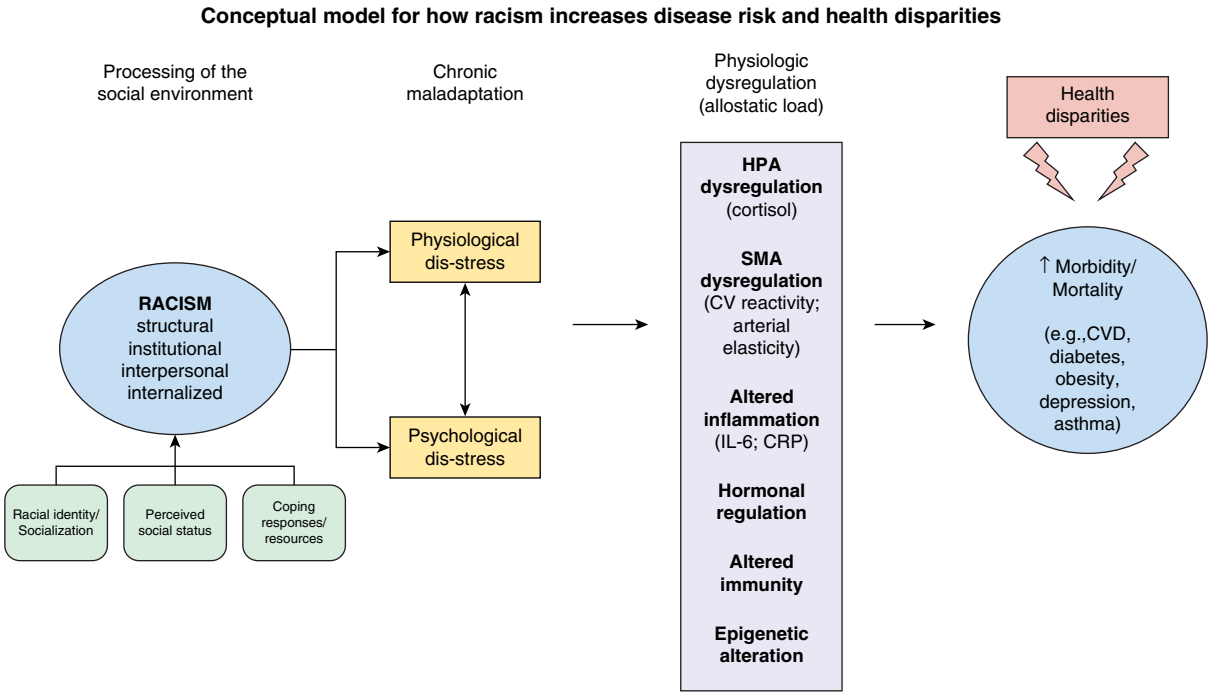

Fig. 2.3 Mechanism through which racism leads to health disparities.

stress and result in physiologic stability in the face of an external challenge. After an acute external stress or challenge, these systems revert to normal baseline states.

However, when the stressor becomes chronic and unbuffered by social supports, dysregulation of these systems may occur, resulting in pathophysiologic alterations to these responses, such as hyperactivation of the allostatic systems, or *burnout*. Over time this dysregulation contributes to increased risk of disease and dysfunction. This pathophysiologic response is called *allostatic load*.

Allostatic load may contribute to increased incidence of chronic diseases such as cardiovascular disease, stroke, diabetes, obesity, asthma, and depression. It is notable that these specific chronic diseases have increased prevalence in racial and ethnic minority groups because of long-standing historical and current discrimination and oppression that have contributed to increased psychologic distress that in turn contributes to allostatic load and the resultant disparities in these chronic diseases. Many of these conditions are noted to occur in adulthood, demonstrating the life course consequences of chronic psychosocial stress and adversity that begins in childhood. Figure 2.3 shows a model through which racism as a toxic psychosocial stressor "gets under the skin" to cause physiologic dysregulation (allostatic load), which over time leads to chronic illnesses that are known to have higher prevalence in minoritized populations (health disparities).

The allostatic load model provides a pathophysiologic mechanism through which negative structural and social determinants of health contribute to health disparities. It complements other mechanisms noted in Figure 2.2, such as differential access to healthcare; increase in health risk behaviors; and increased exposure to pathogens, toxins, and other unhealthy agents.

The Healthy Immigrant Paradox

The Healthy Immigrant Paradox refers to the epidemiologic finding that first-generation immigrants have better health than native-born counterparts regardless of age, sex, economic status, or ethnic category, but their health status declines and converges with the native-born population over time. Studies in the United States and Europe have found that most immigrants have better physical and psychologic health status than native-born people of similar ethnicity in their receiving country. There are a variety of possible explanations for this health difference, including self-selection bias among people who emigrate: being younger, more educated, and physically healthier than those in the country of origin who do not emigrate. In addition, immigrants may bring healthier cultural beliefs and practices that may contribute to better health outcomes. However, the health status of immigrant populations declines in the decades after initial migration because of a variety of complex sociopolitical and economic reasons, including denial of access to healthcare services (e.g., laws that prohibit immigrants from having access to preventive health services), having jobs with unsafe work conditions, adopting poorer health habits, and the psychologic stress of adapting to a new society (i.e., acculturation stress) (see Fig. 12.1).

The Healthy Immigrant Paradox is not universal and has been called into question by some. Many studies of the Healthy Immigrant Paradox use self-report of health status, which may be prone to bias. Not all first-generation immigrants demonstrate better health than their U.S.-born counterparts. Immigrant health status can be influenced by country-of-origin factors (e.g., war, famine), health beliefs (e.g., perceiving obesity to be a sign of wealth rather than of poor health), and racialized immigration policies in the receiving country that favor immigrants from some countries over others. Many studies of the Healthy Immigrant Paradox do not include temporary immigrant workers who often do not have the same access to resources as do longer-term immigrants.

Approximately 18.4 million, or 25% of children in the United States under age 12 years, have at least one immigrant parent. Children of immigrant parents have better health and academic outcomes compared with their U.S.-born counterparts. For example, Latinx and Asian children who are born to immigrant parents (second generation) and those brought to the United States as children (1.5 generation) have better study habits and better academic outcomes compared with third-generation U.S.-born Latinx and Asian American counterparts. Behavioral health outcomes also vary among immigrant children and their U.S.-born counterparts, where third-generation and subsequent generation children engage in more risky health behaviors.

DISPARITIES IN CHILD HEALTH AND HEALTHCARE

Tables 2.1 and 2.2 display some of the known disparities in child health and healthcare. Many health disparities may occur as a result of historical oppression and marginalization of people with policies targeting groups

Table 2.1 Child Health Disparities

HEALTH INDICATOR	RACE/ETHNICITY	FAMILY INCOME	RESIDENCE
Child health status fair or poor	Black and Hispanic > White and Asian	Poor > Not Poor	
Children with special healthcare needs (CSHCN)	Black > White > Hispanic	Poor > Not Poor	
One or more chronic health conditions	Black > White > Hispanic > Asian	Poor > Not Poor	
Asthma	Mainland Puerto Rican > Black > White and Mexican American	Poor > Not Poor	Urban > Rural
Obesity	Hispanic and Black > White and Asian	Poor > Not Poor	Rural > Urban
Infant mortality	Black > Hispanic > White	Poor > Not Poor	
Low birthweight (<2,500 g)	Black > White, Hispanic, American Indian/ Native Alaskan, Asian/Pacific Islander Mainland Puerto Rican > Mexican American	Poor > Not Poor	
Preterm birth (<37 wk)	Black > American Indian/Native Alaskan, Hispanic, White, Asian/Pacific Islander Mainland Puerto Rican > Mexican American	Poor > Not Poor	
Seizure disorder, epilepsy	Black > White, Hispanic	Poor > Not Poor	
Bone, joint, or muscle problem	White > Black, Hispanic	Poor > Not Poor	
Ever breastfed	White, Hispanic, Asian > Black	Not Poor > Poor	Urban > Rural
No physical activity in the past week	Hispanic > Black, Asian > White	Poor > Not Poor	
Hearing problem		Poor > Not Poor	
Vision problem		Poor > Not Poor	
Oral health problems (including caries and untreated caries)	Hispanic > Black > White, Asian	Poor > Not Poor	Rural > Urban
Attention-deficit/hyperactivity disorder (ADHD)	White, Black > Hispanic	Poor > Not Poor	Rural > Urban
Have ADHD but not taking medication	Hispanic, Black > White		
Anxiety problems	White > Black, Hispanic	Poor > Not Poor	
Depression		Poor > Not Poor	Rural > Urban
Behavior or conduct problem (ODD, conduct disorder)	Black > White, Hispanic	Poor > Not Poor	
Autism spectrum disorder	White > Black > Hispanic	Poor > Not Poor	
Learning disability	Black > White, Hispanic	Poor > Not Poor	Rural > Urban
Developmental delay	Black > White > Hispanic, Asian	Poor > Not Poor	
Risk of developmental delay by parental concern	Hispanic > Black and White	Poor > Not Poor	
Speech or language problems		Poor > Not Poor	
Adolescent suicide attempts (consider, attempt, needed medical attention for an attempt)	Girls: Hispanic > Black and White Boys: Hispanic and Black > White		
Adolescent suicide rate	Girls: American Indian > White, Asian/Pacific Islander, Hispanic, Black Boys: American Indian and White > Hispanic, Black, Asian/Pacific Islander		
Child maltreatment (reported)	Black, American Indian/Alaskan Native, Multiracial > White, Hispanic, Asian, Pacific Islander	Poor > Not Poor	
Flourishing	Asian American > White > Other Non-Hispanic > Black >Hispanic	Not Poor > Poor	
AIDS (adolescents)	Black > Hispanic > White		

AIDS, Acquired immunodeficiency syndrome; ODD, oppositional defiant disorder.

Table 2.2 Child Healthcare Disparities

HEALTHCARE INDICATOR	RACE/ETHNICITY	FAMILY INCOME	RESIDENCE
Did not receive any type of medical care in past 12 mo	Hispanic, Black, Asian > White	Poor > Not Poor	Rural > Urban
No well-child checkup or preventive visit in past 12 mo	Hispanic > White and Black	Poor > Not Poor	Rural > Urban
Delay in medical care	Hispanic > Black > White	Poor > Not Poor	
Unmet need in healthcare due to cost	Black > Hispanic > White > Asian	Poor > Not Poor	
No coordinated, comprehensive, or ongoing care in a medical home	Hispanic > Black and Asian > White	Poor > Not Poor	Rural > Urban
Problem accessing specialist care when needed	Hispanic and Black > White	Poor > Not Poor	
No preventative dental care visit in past 12 mo	Hispanic and Asian > Black > White	Poor > Not Poor	Rural > Urban
No vision screening in past 2 yr	Hispanic and Asian > Black and White	Poor > Not Poor	
Did not receive needed mental health treatment or counseling in past 12 mo	Black and Hispanic > White	Poor > Not Poor	
Not receiving a physician recommendation for HPV vaccination among 13- to 17-yr-old girls	Black and Hispanic > White		
Immunization rates: adolescent HPV vaccine	Girls: white > Black and Hispanic Boys: Black and Hispanic > White		

HPV, Human papillomavirus.

that are deemed to be socially, politically, geographically, and economically inferior. As a result of these targeted policies, we tend to see health disparities of people based upon racial/ethnic group, socioeconomic status (often operationalized through family income, sometimes using insurance status as a proxy), and residency patterns, such as urban and rural locale. Other stratification factors, such as ability/disability status, may also contribute to health and healthcare inequality

Child Health Disparities

Asthma

Disparities in asthma prevalence are seen by racial/ethnic group and SES. According to the CDC's 2019 National Health Interview Survey (NHIS) data, the national mean prevalence of asthma among children (<18 years old) was 7.0%. Compared with the mean, the children with the highest prevalence of asthma were Black (18.0%), Indigenous Nation/Alaskan Native (17.8%), and Hispanic (12.5%). Asthma prevalence for Asian American children was 8.2%. There are also significant regional and SES differences in asthma prevalence, with children who live below the federal poverty level having a 14.5% prevalence.

Exposure to environmental pollutants is one factor explaining these disparities in asthma prevalence. Although non-Hispanic White Americans consume the most goods and services that produce greenhouse gases (e.g., fine particulate matter), Black and Hispanic Americans have higher exposure to greenhouse gases that are associated with poor health outcomes, including asthma. Residential hypersegregation results in higher exposure to air pollution and other respiratory toxins for Black and Hispanic Americans, increasing their risk of asthma. In addition, evidence shows a correlation between exposure to traffic pollutants and having fewer local pharmacies and healthcare providers. This "triple jeopardy" is more common with Black and Hispanic children.

Obesity

In 2018, the National Center for Health Statistics found that 19.3% of all U.S. children and adolescents (ages 6-17 years) have obesity (Fig. 2.4). Obesity prevalence was highest among Hispanic children (25.6%) and non-Hispanic Black children (24.2%). The prevalence of obesity was 16.1% among non-Hispanic White children and 8.7% among non-Hispanic Asian children. The obesity prevalence among Indigenous Nation/Alaskan Native adolescents is 11.0% and among Native Hawaiian/Pacific Islanders is 26.7%. There are complex interplays between social, environmental, and behavioral influences on health that contribute to obesity disparities in the United States. Studies

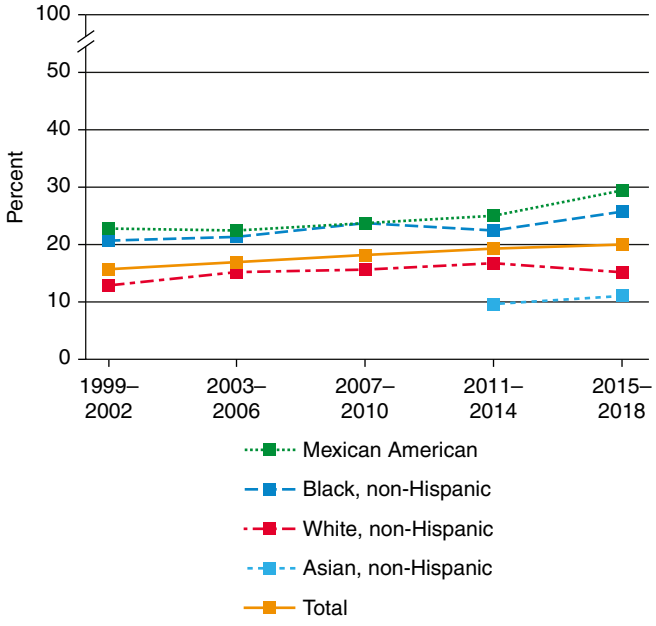

Fig. 2.4 Percentage of children ages 6-17 with obesity by race and Hispanic origin, selected years 1999–2002 through 2015–2018. (*From National Center for Health Statistics. National Health and Nutrition Examination Survey.* https://www.childstats.gov/americaschildren/surveys2.asp#nhnes.)

have found that obesity prevalence is higher in communities with high rates of poverty and communities with a majority Black population because of lack of access to grocery stores and farmers markets (food deserts), overabundance of fast-food restaurants, less access to parks and outdoor recreation areas, food marketing targeting, and higher healthy food prices. In addition, dietary patterns, access to nutritious foods, and differing cultural norms regarding body habitus may account for some of these differences.

Pregnancy Outcomes, Preterm Birth, and Infant Mortality

The highest rates of infant mortality are seen in non-Hispanic Black infants (Figs. 2.5 and 2.6). According to data from the CDC, the overall

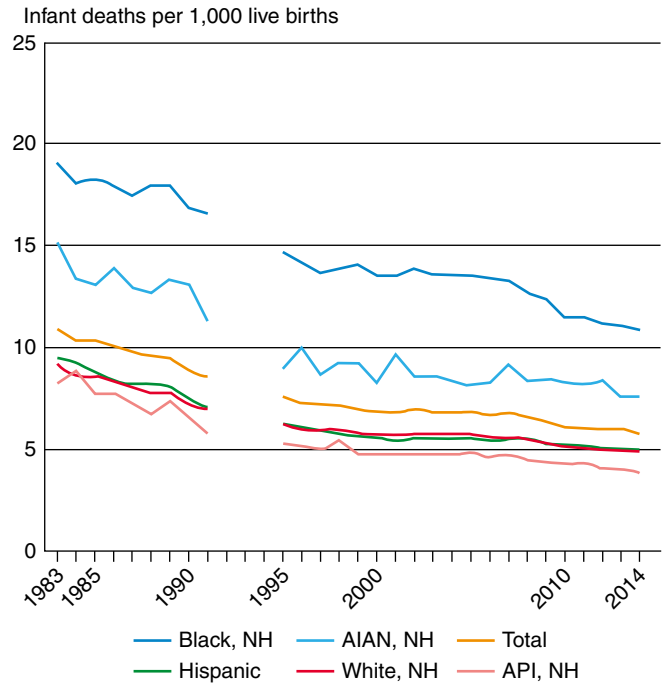

Fig. 2.5 Death rates among infants by race and Hispanic origin of mother, 1983–1991 and 1995–2014. AIAN, American Indian or Alaska Native; API, Asian or Pacific Islander; NH, non-Hispanic. (*From National Center for Health Statistics. National Vital Statistics System.* https://www.childstats.gov/americaschildren/health_fig.asp#health2. *Accessed July 2018.*)

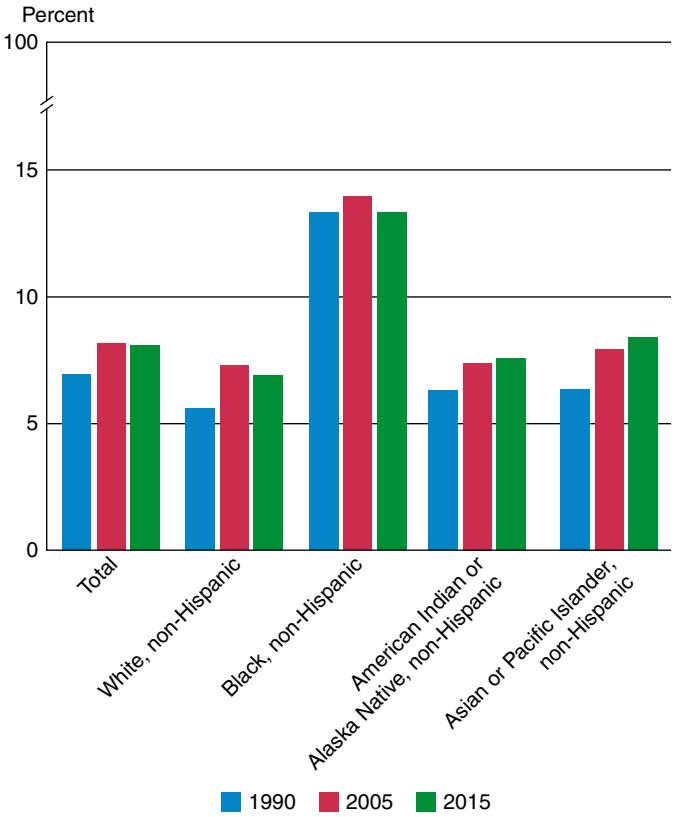

Fig. 2.6 Percentage of infants born with low birthweight by race and Hispanic origin of mother, 1990, 2005, and 2015. (*From National Center for Health Statistics. National Vital Statistics System.* https://www.childstats.gov/americaschildren/health_fig.asp#health1b. *Accessed July 2018.*)

infant mortality rate was 5.7 infants per 1,000 live births. For Black infants, the mortality rate was 10.8 infants per 1,000 live births. The top 5 causes of mortality (in order of frequency) among Black infants were low birthweight, congenital malformations, maternal complications, sudden infant death syndrome (SIDS), and unintended injuries. Black American infant mortality remains high compared with other populations, regardless of maternal education, insurance status, maternal age, and income.

Chronic experiences with structural, institutional, and interpersonal racism contribute to elevated biomarkers for stress and allostatic load, which is referred to as *weathering*—the accumulative effect of adversity on the health of individuals (see Chapter 2.1). Weathering of Black women has been associated with a risk of preterm birth and infant mortality. When examining the life-course perspective, studies suggest that early life exposure to adversity, including systemic racism, increases the risk of poor birth outcomes (see Chapter 2.1). Having a racially concordant physician significantly reduces the risk of infant mortality by 39% among Black newborns.

Infant mortality rates among Indigenous Nation/Alaskan Native populations was 8.2 infants per 1,000 live births, with the leading causes of infant death (in order of frequency) being low birthweight, congenital malformations, and maternal complications. Asian American infants had the lowest infant mortality rates, at 3.8 infants per 1,000 live births, with the leading causes of death (in order of frequency) being congenital malformations, low birthweight, maternal complications, and unintended injuries. The Asian American population was not disaggregated by country of origin, so granular details regarding this heterogenous American population were not available. Overall Hispanic infant mortality was 4.9 infants per 1,000 live births, but mortality rates varied significantly based upon country of origin from 3.8 to 5.6 per 1,000 live births. Leading causes of death among all Hispanic infants (in order of frequency) were congenital malformations, low birthweight, maternal complications, SIDS, and unintended injuries. The White American infant mortality rate was 4.6 infants per 1,000 live births, with the leading causes of infant mortality (in order of frequency) being congenital malformations, low birthweight, SIDS, unintended injuries, and maternal complications (see Chapters 114 and 114.1).

Infant mortality among the Native Hawaiian/Pacific Islander population was 9.4 infants per 1,000 live births overall. Infant mortality rates varied in the Native Hawaiian/Pacific Islander population when the data were disaggregated by country of origin from 10.1 to 22.5 per 1,000 live births. In 2017, the World Health Organization (WHO), UNICEF, and United Nations (UN) highlighted some of the social and environmental risk factors for such high infant mortality among Pacific Islanders, which include prematurity, birth complications, and severe infections (specifically, pneumonia and diarrheal illnesses). Infant mortality among Native Hawaiians was 9.4 infants per 1,000 live births, and the leading causes of infant mortality were preterm birth and low birthweight, sudden unexplained infant death, congenital anomalies, infection, and injury.

Many of the causes of infant mortality disparities can be mitigated through public policy, public health measures, and healthcare interventions that specifically target populations at highest risk, such as increased access to quality prenatal care, reducing air pollution exposure, and improving physician training to reduce implicit bias and improve communication skills.

Oral Health

Significant differences exist in oral health status and in preventive oral healthcare according to race/ethnicity, SES, and residency locale. The 2019–2020 National Survey of Children's Health (NSCH) found the prevalence of oral health problems among children (ages 1-17 years) to be 17.7% for Hispanic Americans, 16.2% for Black Americans, 15.8% for Asian Americans, 12.1% for White Americans, and 13.2% for other non-Hispanic Americans. The prevalence of oral health problems in this 2019-2020 NSCH were found to be highest among children who live in households with incomes below the federal poverty level (20.3%) compared with children who live in households making >400% of the federal poverty level (8.7%).

Data from the CDC demonstrated that overall prevalence of dental caries decreased for children age 6-11 years: from 21% in the 1994–2004 NHANES survey to 17% in the 2011–2016 survey. The children in the survey who did not show improvements in the prevalence of dental caries were younger children (ages 6-8 years), poor children (both near-poor and children living below the federal poverty level), and non-Hispanic Black children. Preventive oral healthcare may improve rates of caries and treat caries before further impairment ensues. Data from the 2014 Medical Expenditure Panel Survey revealed that being poor and lacking health insurance were the main reasons for not receiving preventive dental care.

Hearing Care

No data suggest that the prevalence of hearing loss (either congenital or acquired) is different among racial/ethnic or SES categories, but follow-up care after diagnosis of a hearing problem has been shown to be poorer in certain groups. Delays in diagnosis and treatment of hearing loss are found among children who lack health insurance, live farther away from diagnostic health centers, are poor, live in areas with specialists' shortages, live in rural areas, and have primary care providers with limited experience in caring for children with hearing loss. Much of this disparity is reduced when families have access to specialists.

Vision Problems

The parent-reported 2019–2020 NSCH found that vision problems were reported in 3.1% of Hispanic children, 1.2% of White children, 2.1% of Black children, 1.0% of Asian children, and 1.6% of children in other racial categories. Vision problems were more commonly reported among children who lived in households with an income that was less than the federal poverty level (3.4%) compared with children living in households with an income greater than 400% of the federal poverty level (0.8%). Vision problems were more commonly reported among children who did not have a medical home (2.6%) compared with children with a medical home (1.0%). Reports of vision problems in children also varied by insurance coverage type, with 0.9% of children with private health insurance, 3.0% of children with public health insurance, 3.0% of children with both public and private health insurance, and 4.1% among uninsured children.

Immunization

Disparities in immunization rates had been noted with household income status, insurance status, and residential location. In response to these socioeconomic disparities and to higher rates of measles cases in the 1980s, a number of interventions were initiated, including the creation of the **Vaccines for Children program** (VFC), which eliminated the financial barrier to immunization by providing free immunizations to at-risk groups (Medicaid-eligible, uninsured, Indigenous Nation/Alaskan Native, or underinsured and vaccinated at a federally qualified health center or rural health clinic). Although vaccination rates have improved, the 2018–2020 CDC National Immunization Survey—Child study found income, geographic, and racial disparities in infant vaccination rates. Vaccination rates were lower among infants living in households with an income below the federal poverty level and infants who lacked health insurance. Vaccination rates varied widely by state and region of the United States.

Although rates of initial *primary* vaccine series demonstrate no or decreasing disparities, other vaccination rates do show differences. Black and Hispanic adolescent females have lower human papillomavirus (HPV) vaccination rates than do Whites. Reasons for this disparity include parental concerns about safety and providers not recommending the vaccine. Of interest, Black and Hispanic male adolescents have higher rates of HPV vaccine coverage than do Whites.

Adolescent Suicide

In 2019, the CDC Youth Behavior Risk Surveillance System of 9th-12th graders reported suicide attempts by racial category, sex, and sexual orientation. The highest rate of suicide attempts was among Indigenous Nations/Alaskan Native teens (25.5%), followed by Native Hawaiian/Pacific Islanders (18.4%), multiracial teens (12.9%), Blacks (11.8%), Latinx Americans (8.9%), White Americans (7.9%), and Asian Americans (7.7%). Suicide attempts were higher among adolescent females (11.0%) than among adolescent males (6.6%). Suicide attempts vary when stratified by sexual orientation status, with the highest prevalence among bisexual teens (24.5%), followed by gay male teens (19.5%) and heterosexual teens (6.4%). Risk factors for suicide ideations and attempts include sexual assault, being bullied, substance abuse, depression, and experiences with interpersonal racial discrimination (see Chapter 40).

Child Maltreatment

In 2014, *reports* of child abuse and neglect were higher in Black (15.3 per 1,000 children), Indigenous Nation/Alaskan Native (13.4/1,000), and multiracial (10.6/1,000) children, compared with Hispanic (8.8/1,000), Pacific Islander (8.6/1,000), White (8.4/1,000), and Asian (1.7/1,000) children. Poverty, measured at the family and at the community level, is also a significant risk factor for maltreatment. Counties with high poverty concentration had >3 times the rate of child abuse deaths than counties with the lowest concentration of poverty. Additionally, it is the "criminalization" of poverty that increases the risk of poor people being reported for abuse and neglect compared to their more affluent counterparts. However, despite the fact that Black children are overrepresented in the child welfare system in the United States, race itself *should not be a marker* for child abuse or neglect. *Studies have found that Black parents are overreported for child abuse and maltreatment compared with White parents who engage in the same behavior because of historical systemic racism and implicit racial bias among those who report and caseworkers.* Latinx children's representation in the child welfare system varies by state and region, where they are overrepresented in some states, but underrepresented in other states. Indigenous Nation/Alaskan Native youth are underrepresented in the child welfare system in most states, but Alaska is the state with the highest overrepresentation of Indigenous children reported to the child welfare system. White American children are not overrepresented in the child welfare system and are often underrepresented.

Behavioral Health Disparities

Attention-Deficit/Hyperactivity Disorder (ADHD)

The 2019–2020 NSCH found the overall prevalence of ADHD among children age 3-17 years to be 8.9%. White and Black children are more often diagnosed with ADHD (10.2% and 10.5%, respectively) than are Hispanic children (6.9%), Asian American children (2.7%), and children of other non-Hispanic groups (8.5%). Other studies have shown that both Black and Hispanic children have lower odds of having an ADHD diagnosis than White children. Children reared in homes with a household income below the federal poverty level are diagnosed more often (10.9%) than those at or above the federal poverty level (8.3%). Children with two or more adverse childhood experiences (ACEs) are almost 3 times as likely to be diagnosed with ADHD (17.1%) compared with children with no ACEs (5.8%). Children without a medical home are more likely to be diagnosed with ADHD (9.7%) compared with children who have a medical home (8.0%).

Children diagnosed with ADHD have different treatment experiences. After being diagnosed with ADHD, White children, when compared with Black and Hispanic children, were more likely to be diagnosed with a coexisting anxiety disorder. Within the first year of treatment for ADHD, White children were most likely to be treated with medication or behavior therapy and Asian American children were the least likely to receive any type of treatment for ADHD.

Depression and Anxiety Disorders

According to the 2020 National Survey of Drug Use and Health, from 2004 to 2019, the reported prevalence of major depression episodes increased among all U.S. adolescents. In 2019, those with the highest reported prevalence of a major depression episode were 16- to 17-year-olds (20.2%), adolescent girls (23.0%), adolescents of two or more races (20.9%), and teens living in households with incomes above the federal poverty level (16.1%).

When stratifying by racial group, a major depression episode was found in 17.3% of Hispanic teens, 15.9% of White teens, 15.1% of Asian American teens, 12.2% of Indigenous Nation/Alaska Native teens, and

11.4% of Black teens. Differences in reported rates of depression based upon racial group may be the result of differences in the manifestation of depression symptoms, clinician treatment bias, and limited access to adequate mental healthcare.

Autism Spectrum Disorder (ASD)

Compared with White children, Black and Hispanic children are less likely to be diagnosed with ASD, and when diagnosed, are typically diagnosed at a later age and with more severe symptoms. Nonetheless, Blacks and Hispanics are typically diagnosed at a later age and with more severe symptoms. Disparities in diagnosis and timing of diagnosis are concerning given that early diagnosis provides access to therapeutic services that are most effective when initiated early. Reasons for these disparities may include differences in cultural behavioral norms, stigma, differences in parental knowledge of typical and atypical child development, poorer access to quality healthcare, and differences in the quality of provider-patient communication along with trust in providers. Recent CDC data suggest that racial and ethnic disparities in ASD diagnosis are decreasing.

Behavioral or Conduct Problems

According to the 2011–2012 NSCH, Black children age 2-17 years have higher rates of oppositional defiant disorder (ODD) or conduct disorder than do White and Hispanic children. Evidence suggests that the *overdiagnosis* of Black children with these disorders is linked to the pervasive criminalization and adultification of Black child behavior. Adults often view Black children as older, less innocent, and in less need of protection than same-age peers of other racial groups. In fact, studies have found that physicians with negative implicit racial bias are more likely to overpathologize Black child behavior and overdiagnose Black children with ODD, conduct disorder, and ADHD. The pathologizing of Black child behavior can have severe consequences, including excessive school punishment, school expulsion, and early contact with the legal system.

Developmental Delay

The 2019–2020 NSCH found that Black children age 3-17 years had higher reported rates of developmental delay (7.4%) than Hispanic children (5.3%), White children (5.4%), and other non-Hispanic children (5.4%). Children living in households with incomes below the federal poverty level were more likely to be diagnosed with a developmental delay (8.7%) than children living in households with an income at 400% of the federal poverty level (3.6%). Children experiencing two or more ACEs have a higher prevalence of developmental delay than do children with no ACEs (10.8% vs 3.8%). ACEs increase the child's allostatic load and impede neurologic development, thus placing them at increased risk of developmental delays. Evidence also suggests that physicians with negative implicit racial biases are less likely to ask Black parents and parents who speak English less fluently about their concerns regarding developmental delays and are less likely to refer the children to early intervention, and these children are less likely to receive appropriate developmental evaluations by early intervention providers.

Flourishing

In the 2019–2020 NSCH, parents reported rates of flourishing, which is overall good mental health in their children and teens. Flourishing was measured by three behaviors: learning, resilience, and self-regulation. Overall, 63.3% of parents reported their child met all three flourishing criteria. Females (66.8%) were reported as having higher flourishing than males (59.9%). The highest level of flourishing was reported among Asian American youth (73.0%), followed by White (64.8%), other non-Hispanic children (62.1%), Black (61.8%), and Hispanic (59.7%). Flourishing rates were lowest among youth who live in households with incomes lower than the federal poverty level (55.6%) and highest among youth living in families with incomes higher than 400% of the federal poverty level (70.0%).

Child Healthcare Disparities

In almost all areas, Black, Hispanic, and Indigenous Nation/Alaskan Native children have been identified as having worse access to needed healthcare, including receipt of any type of medical care within the past 12 months, well-child or preventive visits, delay in care, having an unmet need because of healthcare cost, lack of care in a medical home, problems accessing specialist care when needed, lack of preventive dental care, vision screening, mental health counseling, and recommendations for adolescent immunizations (see Table 2.2). In addition, many of these healthcare indicators are found to be worse for children living in poverty and for those living in a rural area. Disparities in access to and quality of healthcare among children of color and poor children are linked to long-standing structural barriers, systemic racist policies and practices, environmental policies, social and structural determinants of health, and healthcare provider negative implicit racial biases that influence healthcare delivery and patient-physician communication and relationships.

APPROACHES TO ERADICATING DISPARITIES: INTERVENTIONS

An example of a successful intervention that closed the disparity gap is the implementation of the VFC program, which significantly decreased the disparity in immunization rates noted among racial/ethnic groups and poor/underinsured children. This is an example of a **public health policy** approach to intervention.

Interventions need to occur at the **clinical** level as well. The almost-universal use of electronic health records (EHRs) provides a unique opportunity for collecting vital clinical and demographic data that can be helpful in identifying disparities and monitoring the success of interventions. All EHR platforms should use a standardized approach to gathering information on patient race/ethnicity, SES, primary language preferences, and health literacy. The Institute of Medicine's 2009 report *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement* provides best practices information about capturing these data in the health record.

The advancing science of clinical **quality improvement** can also provide a framework for identifying clinical strategies to reduce disparities in care. Use of **PDSA** (Plan-Do-Study-Act) cycles targeting specific clinical issues where health disparities exist can result in practice transformation and help reduce differential outcomes.

Another practice-level intervention that has the potential to reduce disparities in care and outcomes is the **medical home** model, providing care that is accessible, family centered, continuous, comprehensive, compassionate, coordinated, and culturally effective. The use of care coordinators and using community-based health navigators are effective tools in helping to break down the multiple social and health system barriers that contribute to disparities.

Community engagement is an essential requirement for lessening health and healthcare inequities. Health systems, practices, providers, public health, researchers, and payers need to include community voice and representation in all aspects of quality improvement, data interpretation, program design and development, and dissemination. To do less would be "working *on* people" instead of "working *with* people." To use a phrase from the disability advocacy community: *"Nothing about us without us."* Many potential interventions seem appropriate and demonstrate efficacy under ideal circumstances. However, if the intervention does not address the concerns of the end users—patients and communities—or fit the social or cultural context, it will likely be ineffective in the "real world." Only by involving the community from the beginning, including defining the issues and problems, can the likelihood of success be optimized.

At the provider level, there are opportunities for training in implicit bias and communication skills, as discussed in Chapter 2.1. *Shared decision-making* has been found to improve physician-patient relationships and health outcomes. Another strategy to address cognitive biases in physician clinical decision-making is to identify heuristic and other cognitive errors (see Tables 5.3-5.5) and use the diagnostic time-out (see Table 5.6) when a diagnosis does not fit the clinical presentation.

Population health strategies have the advantage of addressing the determinants of disparities at both the clinic and community levels. Techniques such as hotspotting, cold-casing (finding

patients and families lost to follow-up and not receiving care), and geocoding; collaborating with communities and community-based organizations; and periodic community health needs assessments identify the structural, systemic, environmental, and social factors that contribute to disparities and help guide interventions that are tailored to the local setting.

Health disparities are a consequence of social and structural determinants of health that often have developed based on historically racist policies and other practices and traditions that led to the social stratification mechanisms inherent in many modern societies. Health disparities mirror other societal disparities in education, policing, employment opportunities, and living conditions. While society grapples with the broader issues contributing to disparities, healthcare and public health can work to understand the multiple causes of these disparities and develop interventions that address the structural, clinical, and social root causes of these inequities.

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2.1 Racism and Child Health

Mary T. Bassett, Zinzi D. Bailey, and Aletha Maybank

RACISM AS A SOCIAL DETERMINANT OF HEALTH AND HEALTH INEQUITIES

An emerging body of evidence supports the role of racism in a range of adverse physical, behavioral, developmental, and mental health outcomes. Racial/ethnic inequity in health outcomes in the United States is long-standing, apparent from the first collection of vital statistics in the colonial period. However, the extensive data that document racial disparities have not settled the question of why groups of people, particularly of African and Indigenous Nations peoples ancestry, face increased odds of shorter lives and poorer health (see Tables 2.1, 2.2, and 2.3). The role of societal factors is well recognized in determining population health, but often omits racism among social determinants of health. This oversight occurs in the face of a long history of racial and ethnic subjugation in the United States that has been justified both explicitly and implicitly by racism. From the early 18th century, colonial America established racial categories that enshrined White supremacy, conferring rights specifically on White men, while denying these rights to others. This "racial" designation was social and not based on genetics. Similar, perhaps less explicit, discrimination has continued through the centuries and remains a primary contributor to racial/ethnic inequities in children's health. Current lifelong exposure to interpersonal, structural, and institutional racial discrimination and subordination has a significant impact on Black health outcomes.

For generations, racial/ethnic disparities have been documented beginning at birth and extending across life. In 2018, life expectancy at birth for Blacks was almost 4 years shorter than life expectancy of non-Hispanic Whites, influenced heavily by disparities starting at birth (Table 2.3). The **infant mortality rate** (IMR), arguably the most important measure of national health, has shown a persistent Black-White gap despite a substantial decline in U.S. IMR for all racial/ethnic groups (see Fig. 2.5). NCHS data in 2022 showed a double-digit IMR *only* among non-Hispanic Blacks, with 10.38 deaths per 1,000 live births, compared to 4.4/1,000 for non-Hispanic Whites. A troubling stagnation in IMR, with no recent decline, is found among Alaska Natives and Indigenous Nations peoples. The 2022 IMR among non-Hispanic Indigenous Nation peoples or Alaskan Native individuals, 7.68 deaths/1,000 live births, has remained essentially unchanged for almost 2 decades.

Exposures that affect infant survival occur before birth. Much of the maternal and child health literature emphasizes a higher prevalence of maternal obesity, diabetes, and substance/alcohol use before conception among Black women as individualized risk factors leading to disparities in birth outcomes (Chapter 114.1). A California study of maternal obesity found that 22.3% of pregnant Black women and 20.3% of Latina women had a body mass index (BMI) of 30-40, compared with 14.9% of White and 5.6% of Asian women. BMI >40 was more than twice as prevalent in Black (5.7%) than in White (2.6%) women. Further, in a nationally representative study of over 7 million singleton live births from the 2016 and 2017 U.S. National Vital Statistics System, although maternal prepregnancy obesity was associated with the risk of preterm birth in the general population, risk varied by maternal age and race/ethnicity. Maternal obesity among non-Hispanic Black women was inversely associated with risk of preterm birth among those younger than 30 years, but positively associated among those age 30 and older. Similar relationships were shown for non-Hispanic White and Hispanic women. Although individual risk factors such as obesity contribute to differences in birth and health outcomes, individual risk factors alone do not sufficiently explain these differences. Further, a focus on individual risk factors may contribute to a narrative that places blame on the individual without acknowledging the structural and social conditions of patients' lives influencing the prevalence of these risk factors. Proximal factors such as maternal obesity do not capture the root causes of early childhood health inequities, **social determinants of health**, which present intervention points for achieving health equity.

Achieving health equity requires examining equity in outcomes *and* also equity in process. Causes and interventions to address health inequities can be conceptualized as occurring upstream, downstream, or somewhere in between (Fig. 2.7). Downstream determinants occur on individual levels, including individual biology and specific risk factors and behaviors. In Figure 2.7, measures of health and health inequities, like life expectancy, IMR, maternal obesity, and maternal age, are at the far right and are considered downstream factors. Clinical interventions focused on downstream factors may help individuals, but do not address factors upstream that drive inequities in population health outcomes.

These upstream factors include the physical, social, work, and service environments in which people are born, grow, live, work, and age that lead to downstream outcomes. If a child lives in public housing that is systematically underresourced to eliminate common pests, that child is more likely to encounter asthma triggers, experience asthma attacks, and require emergency department care or hospitalization. Interventions could include remediating one apartment or home or increasing access to insurance; however, this is not getting at systematic mechanisms by which public housing becomes a social determinant of health. Moreover, these interventions do not address the reasons that families need public housing in the first place or why these living conditions are more prevalent among certain communities compared with others.

The distribution of these living conditions is patterned by institutional inequities in the public and private sectors and in our laws and regulations, which represent a wider set of forces and systems shaping the conditions of daily life. Social inequities, like racism, sexism, classism, heterosexism, and ableism, represent upstream social determinants of health that affect access to resources and healthy living conditions and are inequitably distributed across preexisting hierarchies of power. Resource allocation for public housing and the absence of universal access to a living wage might drive the living conditions within public housing. Focusing solely on downstream results of larger inequitable structures seldom yields sustainable change and ignores the roots of health inequities while tending to blame individuals structurally constrained by centuries of inequitable systems.

Prenatal maternal exposures to pesticides, lead, and other environmental toxins vary by race. This inequitable distribution is largely driven by racist policies and practices affecting exposures to small- and large-scale environmental hazards (see Chapter 2). The effects of persistent racism are stressful and toxic to the body, with the experience of discrimination across leading to biologic changes that persist the life span, especially for pregnant women and their children. Thus racism is an essential social determinant of racial/ethnic inequities in maternal and child health. Racism can increase cortisol levels and lead to a cascade of effects, including impaired cell function, altered fat metabolism, increased blood glucose and blood pressure, and decreased bone formation (see Chapter 1 and Fig. 2.3). This can affect a growing fetus,

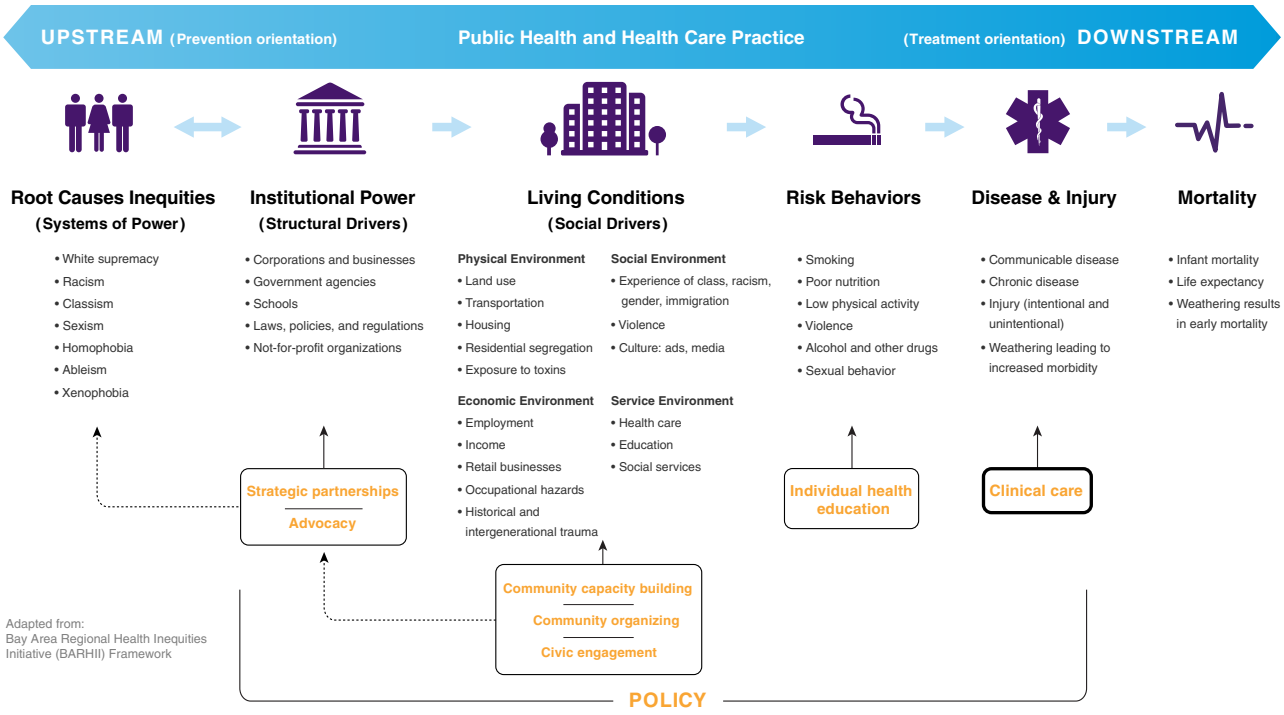
Table 2.3 New Social and Health Inequities in the United States

	TOTAL	WHITE NON-HISPANIC	ASIAN*	HISPANIC OR LATINO	BLACK NON-HISPANIC†	NATIVE AMERICAN OR ALASKA NATIVE
Wealth: median household assets (2019)	$118,200	$187,300	$206,400	$31,700	$14,100	NR
Poverty: proportion living below poverty level, all ages (2019)	12.3%	9.0%	9.7%	17.2%	21.2%	24.2%
Poverty: proportion living below poverty level, children <18 yr (2019)	16.0%	10.0%	9.0% for Asians only; 18.0% for Pacific Islanders	23.0%	30.0%	30.0%
Unemployment rate (2021)	5.2%	4.6%	4.7%	6.2%	8.4%	NR
Incarceration: male inmates per 100,000 (2010)	733	450	115 for Asians only; 1,017 for Native Hawaiians and other Pacific Islanders	831	2,306	1,291
Proportion with no health insurance, age <65 yr (2018)	11.0%	7.8%	7.4%	20.1%	12.1%	28.6%
Infant mortality per 1,000 live births (2018)	5.7	4.6	3.9 for Asians only; 9.4 for Native Hawaiian and other Pacific Islander	4.9	10.8	8.2
Preterm Birth: proportion of singleton births before 37 wk gestation (2018)	8.2%	7.2%	7.1%	8.4%	11.9%	10.2%
Maternal mortality, deaths per 100,000 live births (2018)	17.4	14.9	NR	11.8	37.3	NR
Proportion of children <18 yr reporting current asthma (2018)	7.5%	5.6%	3.6%	8.0%	14.3%	NR
Self-assessed health status (age-adjusted): proportion with fair or poor health (2018)	9.0%	7.6%	8.2%	12.3%	13.5%	18.6%
Potential life lost: person-years per 100,000 before age 75 yr (2016)	7,431.7	7,021.0	3,176.8	4,926.0	10,505.2	7,360.2
Proportion reporting serious psychologic distress‡ in past 30 days, age ≥18 yr, age-adjusted (2015–2016)	3.6%	3.7%	2.1%	3.7%	3.6%	9.2%
Life expectancy at birth (2018), yr	78.7	78.6	NR	81.8	74.7	NR
Diabetes-related mortality: age-adjusted mortality per 100,000 (2018)	21.4	18.9	15.4 for Asians only; 48.1 for Native Hawaiians and other Pacific Islander	24.6	39.3	32.1
Mortality related to heart disease: age-adjusted mortality per 100,000 (2018)	163.6	168.1	82.0 for Asian alone; 161.4 for Native Hawaiian and other Pacific Islander	112.3	212.0	109.6

*Economic data and data on self-reported health and psychologic distress are for Asians only; all other health data reported combine Asians and Pacific Islanders, unless otherwise noted.
†Wealth, poverty, and potential life lost before age 75 yr are reported for the Black population only; all other data are for the Black non-Hispanic population.
‡Serious psychologic distress in the past 30 days among adults 18 yr and older is measured using the Kessler 6 scale (range: 0-24; serious psychologic distress ≥13).
NR, Not reported.
Sources: Wealth data taken from the U.S. Census; poverty data for adults taken from the Kaiser Family Foundation, and poverty data for children taken from the National Center for Education Statistics; unemployment data taken from the U.S. Bureau of Labor Statistics; incarceration data taken from the Prison Policy Initiative using U.S. Census Bureau data; data on uninsured individuals, infant mortality, self-assessed health status, potential life lost, serious psychologic distress, current asthma, preterm birth, life expectancy, diabetes-related mortality, and mortality related to heart disease taken from the National Center for Health Statistics.

leading to increased infant cortisol levels, lower birthweight (LBW), and prematurity. In New York City, White women had lower rates of adverse birth outcomes: 1.3% had preeclampsia, less than half the rate for Black women (2.9%).

Although infant deaths occur more frequently among low-income groups of all races/ethnicities, these birth outcome disparities by race/ethnicity are found also in Blacks with higher SES. College-educated Black women are more likely than White high school–educated women to have a LBW infant, a principal risk factor for infant death. Another study examined California birth certificates of pregnant Arab American women after the September 11, 2001, terrorist attacks and found that those who experienced discrimination immediately after the 9/11 attacks had a higher relative risk of giving birth to an LBW infant in the following 6 months than seen in births before this date. A similar association between exposures to discrimination-based violence and Latina mothers giving birth to LBW infants was found after the largest federal immigration incident in U.S. history in Postville, Iowa, with infants having a 24% greater risk at being LBW



* Upstream refers to acknowledging and addressing the structural, societal, community and individual-level factors that influence health. Whereas downstream refers to the dominant approach of treating individual-level factors and/or contributors without wholly addressing structural, societal, and community factors.

Fig. 2.7 What creates health framework. *(From American Medical Association. Organizational Strategic Plan to Embed Racial Justice and Advance Health Equity, 2021–2023; adapted from the Bay Area Regional Health Inequities Initiative [BARHII] Framework.)*

at birth. These findings reinforce the critical role the physician has in explicitly asking families about potential exposures to racialized stressors and trauma.

The increased risk of disease for populations of color continues from infancy into childhood (see Table 2.1); racial/ethnic disparities are seen across almost all health indicators, with most relative gaps remaining stagnant or worsening over the past two decades. Compared with White children, Black children are about twice as likely to be diagnosed with **asthma**, more likely to be hospitalized for its treatment, and more likely to have fatal attacks. The Black-White disparity in asthma has grown steadily over time. Indigenous Nations children and youth (≤19 years) also experience negative health outcomes, with the highest rates of **unintentional injury** and mortality rates at least twice as high as for other racial/ethnic groups. Additionally, according to a 2017 NCHS brief, Latino youth age 2-19 have the highest rates of **obesity** in the 2000 CDC sex-/age-specific growth charts. The NCHS data show that 25.8% of Latino (followed by Black) children qualified as obese from 2015 to 2016. Black children are more likely to be exposed to witnessed, personal, or family **violence** (an example of an **adverse childhood experience**), and exposure to these stressful life experiences is associated with academic, behavioral, and health problems. Notably, children with more stressful life experiences have a higher likelihood of experiencing ear infections, acute respiratory infections, obesity, eczema, viral infections, and teen pregnancy.

EXPLAINING RACIAL DISPARITIES: A TAXONOMY OF RACISM

Explanations of these ubiquitous racial gaps have focused on individual factors, including variation in individual genetic constitution, behavioral risks, poverty, and access to (and use of) healthcare services. Scientists agree that "race" is a social construct that is not based on biology, despite the persistence of the idea that racial categories reflect a racially distinctive genetic makeup that has a bearing on health. In fact, the genetic variation between individuals within a particular racial/ethnic group is far greater than the variability between "races." Further, biologic ancestry is distinct and separate from the social construct of race. Despite the genetic data, many groups have been "racialized" over time. Notably, the U.S. Census Bureau's demographic classifications reflect this process. In the mid-to-late 1800s the census counted "mulattos," those of White and Black ancestry, as another race.

Starting in the late 19th century, Eastern European immigrants and Jews were considered different races. As early as 1961, the U.S. Census identified Mexicans and Puerto Ricans as "White" even as racial classification varied by geography. All states collected birth records by 1919, but there was little uniformity on how race was collected, if at all, across states. It was not until 1989, when the National Center for Health Statistics (NCHS) recommended assigning "infant race" as that of the mother and that standard guidance and categories were issued for states on collecting racial data at birth. Existing categories were changed and continue to change based on the economic, cultural, or political utility of the time, rather than actual genetic distinction.

Defining Racism

Racism has consistently structured U.S. society and is based on "White supremacy," a hierarchical idea that Whites, the *dominant* group, are intrinsically superior to other groups who are not classified as "White" No single definition of racism exists, but one useful description is *racial prejudice backed by power and resources*. This conceptualization asserts that not only must there be prejudice but

Table 2.4 Pathways Between Racism and Health and Examples

Economic injustice and social deprivation
Residential, educational, and occupational segregation to lower-quality neighborhoods, schools, and jobs (both historical de jure discrimination and contemporary de facto discrimination)
Lower salary for same work
Lower promotion rate despite comparable evaluations
Environmental and occupational health inequities
Placement of bus garages and toxic waste sites
Selective government failure to prevent lead in drinking water (per Flint, Michigan, 2015–2016)
Disproportionate exposure of workers of color to occupational hazards
Psychosocial trauma
Interpersonal racial discrimination, including microaggressions*
Exposure to racist media, including social media
Targeted marketing of health-harming substances
Legal: cigarettes; sugar sweetened beverages
Illegal: heroin; illicit opioids
Inadequate healthcare
Inadequate access to health insurance and healthcare facilities
Inadequate treatment caused by implicit or explicit racial bias
State-sanctioned violence and alienation from property and traditional lands
Police violence
Forced urban "renewal" (use of eminent domain to force relocation of urban communities of color)
Genocide and forced removal of Native Americans
Political exclusion
Voter restrictions (e.g., for ex-felons, ID requirements)
Maladaptive coping behaviors
Increased tobacco and alcohol consumption
Stereotype threat
Stigma of inferiority leading to physiologic arousal
Impaired patient-provider relationship

*Small, often unintentional racial slights/insults (e.g., a judge asking a Black defense attorney, "Can you wait outside until your attorney gets here?")

From Bailey ZD, Krieger N, Agénor M, et al. Structural racism and health inequities in the USA: Evidence and interventions. *Lancet*. 2017;389:1453–1463. Panel 2.

also an interlocking system of institutions to produce and reproduce inequities in access to and use of resources and decision-making power. Even when considering variations in health behavior, lifestyles, economic status, and healthcare use, individual-level behavioral factors do not capture how broader shared social experiences shape outcomes. **Racial domination** or racism contributes to variation in the population's access to resources and exposure to disease and to the group experience of fair treatment and opportunity. Although many groups in the United States may encounter discrimination based on race/ethnicity, most of the modest literature on health effects of racism has focused on people of African descent, leaving a need to better understand the impact of racism on people of color. Table 2.4 and Figure 2.3 describe various pathways through which racism affects health.

Although the empirical data on disparities for non-Black populations of color deserve greater research, useful frameworks exist to understand the disparities that public health has documented to date. A useful taxonomy of how racism operates in society has four categories: internalized racism, interpersonal racism, institutional racism, and structural racism. Each is relevant in considering the impact of racism on child health.

Internalized Racism

When the larger society characterizes marginalized racialized groups as "inferior," these negative assessments may be accepted by members of those groups themselves, either consciously or unconsciously. The result is *devaluation* of personal abilities and intrinsic worth, in addition to the capacity, of others also classified as being a part of a marginalized racialized group. The best-known documentation of *internalized racism* comes from the study of Kenneth and Mamie Clark known as the **doll experiment**, conducted in the 1940s. Black children, both males and females, were asked to choose between a Black doll and a White doll according to attributes described by the interviewer. In response to positive attributes (e.g., *pretty, good, smart*), most children chose the White doll. The Clarks interpreted this finding to mean that Black children had internalized the societal views of Black inferiority and White superiority, even at the expense of their personal self-image. Repeated by a New York City high school student several decades later, the findings were much the same, with 15 of 21 children endorsing positive attributes to light-skinned dolls. Multiple studies confirm that racial identity is established in young children, both Black and White, along with negative views of blackness. Developmentally, however, youth of color often explore racial identity earlier than their White counterparts. In terms of health outcomes, depending on perceived inferiority or superiority of the group, racial identification is associated with self-esteem, mastery, and depressive symptoms. Low self-esteem is independently implicated in mental health disorders and may contribute to the phenomenon of **stereotype threat**, in which personal *expectation of underperformance* correlates with prevailing social stereotypes and adversely affects actual performance.

Interpersonal Racism

How racial beliefs affect interactions between individuals has been the most-studied aspect of racism. *Interpersonal racism* refers to situations where one person from society's privileged racial group acts in a discriminatory manner that adversely affects another person or group of people. Such actions may be based on *explicit* beliefs or on *implicit* beliefs of which the perpetrating individual is not consciously aware. The experience of unfair and prejudicial treatment has *biologic* consequences, reflected in measurable increases in stress responses.

Such effects of interpersonal racism are best documented for **mental health**, where perceived unfair treatment serves as psychosocial stressors, and are less robust for physical health outcomes. A 2021 study of 10,354 U.S. children age 10 and 11 years found only 2.8% of Whites, 5.4% of Latinos, 6.2% of Asian and Pacific Islanders, 6.5% of Indigenous Nations peoples, and 10% of Blacks self-reported enduring racial discrimination. Furthermore, discriminatory experiences have been strongly and consistently linked to greater risk for anxiety, depression, conduct disorder, psychologic distress, ADHD, ODD, low self-esteem or self-worth, and challenges to psychologic adaptation and adjustment (see Chapter 2). Perceived racial discrimination can affect behavioral, mental, and physical health outcomes and is associated with increased alcohol and drug use among Indigenous Nations peoples (age 9-16 years), increased tobacco smoking for Black youth (11-19 years), higher depressive symptoms among Puerto Rican children, and insulin resistance among young females.

Understanding the enduring impact of childhood experience on adult health has increased with the study of ACEs (see Chapter 1). ACEs have well-documented cumulative negative health effects that occur across the life span and are patterned by race/ethnicity. Early experience of racism is a proxy measure for **toxic stress**. The question, "Was [child's name] ever treated or judged unfairly because of their race or ethnic group?" is included in the U.S. Census Bureau's NSCH, a random sample of over 90,000 households to assess the

health of children up to 17 years old. Children of color from low-income households, especially Latino children, were reported to have the lowest level of health. However, higher SES did not protect children exposed to racism from experiencing relatively poorer health. Children exposed to racism were also more likely (by 3.2%) to have a diagnosis of ADHD and were 2 times more likely to experience anxiety and depression.

Toxic stress increases cortisol levels in the body, increasing the risk of chronic disease. One study revealed that adolescents who reported average or high levels of perceived discrimination experienced exaggerated cortisol output in response to negative affect, whereas those reporting low levels of perceived discrimination did not experience significant reactivity to negative affect, after controlling for other stressors. Adolescents who experience racism with no support have been shown to have higher levels of blood pressure and obesity than those with emotional support, which can be protective.

Medical practice has not been exempted from occurrences of interpersonal racism. Using variation in adherence to established clinical standards in diagnostic and treatment decisions across racialized groups, researchers have been assessing interpersonal racism in physician-patient interactions. The most comprehensive review of such bias in clinical care remains the study by the U.S. Institute of Medicine, in which the discriminatory treatment was inferred from examination of clinical decision-making rather than from directly observed interactions. For virtually every condition studied, Black patients were less likely to receive recommended care. Such racial bias has been most extensively established in adults but also extends to children. A study conducted in an emergency department found pediatric patients (<21 years) were less likely to receive medically indicated pain medication if they were Black, mirroring the historical misconception of reduced pain sensitivity among Blacks. Within this context, it is unsurprising that perceived interpersonal racism has been linked to healthcare use, including delays in seeking care or filling prescriptions and distrust of the health system. When Black patients receive **concordant care** from Black healthcare providers, their communications, health outcomes, and care are improved when compared with care from White providers.

Perceived and experienced discrimination can be measured by at least six instruments (scales). Questions such as "Are you treated with less respect or courtesy than other people," "Do people act as if they are afraid of you," "Do people act as if they think you are not smart," and "Do you receive poorer service than other people," can be quantified with responses that range from *Almost everyday* to *Never*. High scores have been associated with preterm birth (see Chapter 114.1)

Institutional Racism

Interpersonal racism clearly inflicts harms, but even if completely eliminated, racial inequities would persist because of institutional and structural racism. Broadly, *institutional racism* refers to patterns of discrimination based on policy, culture, or practice and carried out by state and nonstate institutions (e.g., corporations, universities, legal systems, cultural institutions) within various sectors (e.g., housing, education, criminal justice). Key to current residential segregation are banking practices dating to the post-Depression era. As an institution, the education system has been another tragic case of how racism affects children's health. In addition, mass incarceration by the criminal justice system has dramatically increased in the United States while remaining relatively flat in other developed countries (Fig. 2.8). Over a lifetime, approximately 30% of Black men have been imprisoned.

In school, children of color can experience not only individual racism but also institutional racism, as documented by higher rates of disciplinary actions such as suspensions, and at younger ages than White children. According to a 2016 U.S. Department of Education civil rights survey, Black children, who represent only 19% of national preschool students, account for a staggering 47% of out-of-school suspensions. Black preschoolers are 3.6 times more likely to be suspended than their White peers. Black females, representing 20% of the female preschool population, account for 54% of out-of-school suspensions. Many schools have a "zero tolerance" policy for childhood behaviors, which criminalizes minor school infractions.

Unfortunately, this disparity persists as children continue through the school system: for kindergarten to grade 12 (K-12) students, Black children are 3.8 times more likely to face out-of-school suspension than White peers. This inequity is particularly harmful because the educational system feeds into the criminal justice system (school to prison pipeline). Black students are 2.2 times more likely to have either school-related arrests or law enforcement referrals than their White peers. The U.S. Department of Education survey also reveals racial inequities among children with disabilities. For K-12 children with disabilities covered under the Individuals with Disability Education Act, 21% of multiracial females were issued at least one out-of-school suspension, compared with 5% of White females.

Racial disparities in school discipline for minor infractions, disruptive behavior, or disobedience is linked to the concept of **adultification**. In this harmful, often unrecognized racial bias and social stereotype, adults and especially police view Black children (as young as 5-10 year) as older, less innocent, and more culpable than White students of the same age. Black male children are perceived as older, bigger, and more physically threatening than White peers. Black female children are viewed with similar characteristics plus a perception that Black female youth need less nurturing or protection, are more independent, and less innocent.

In addition to the threat to educational and employment prospects, school suspensions also affect children's health. A 2016 brief from the Yale Child Study Center states that early suspensions and expulsions of children harm behavioral and social-emotional development, weakening a child's overall development. Furthermore, these forms of punishment may prevent the treatment of underlying health issues, such as mental health issues or disabilities, and cause increased stress for the entire family.

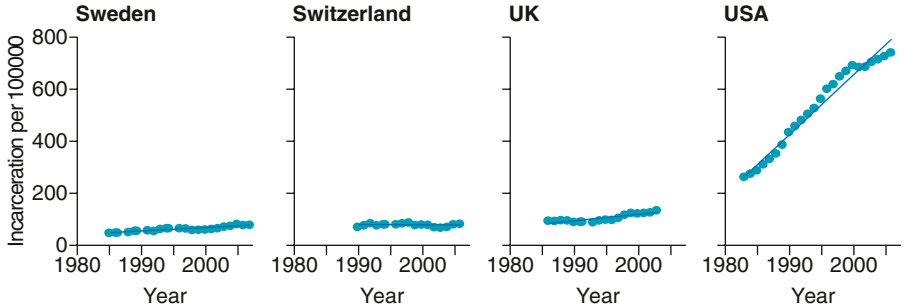


Fig. 2.8 Trends in incarceration prevalence in developed democracies, 1981–2007. (*Adapted from Wilderman C, Wang EA. Mass incarceration, public health, and widening inequality in the USA. Lancet. 2017;389:1464–1472, Fig 1.*)

Institutional racism can function without apparent individual involvement and has powerful repercussions that persist centuries later. Both medical professional organizations and educational institutions have legacies of racial discrimination rooted in *scientific racism*. In 2008 the American Medical Association (AMA) issued a formal apology for its long history, dating to the 1870s, of endorsing explicitly racist practices, including exclusion of Black physicians, silence on civil rights, and refusal to make any public statement on federally sponsored hospital segregation. In 2020, the American Academy of Pediatrics' (AAP) board of directors published an acknowledgement and apology, *Truth, Reconciliation, and Transformation: Continuing on the Path for Equity,* for the institutionalized racist and exclusionary treatment of two Black physicians, Drs. Alonzo deGrate Smith and Roland Boyd Scott, dating back to 1939 and spanning until 1945 when they were finally admitted to the AAP as the first Black members. Exclusion from medical associations also meant exclusion from gaining privileges to work at the majority of hospitals. Despite a focus on medical school desegregation in the 1960s and 1970s, the presence of Black students in medical schools is actually declining. Low enrollment has become especially critical for Black men, who in 2014 accounted for about 500 of the 20,000 medical students nationwide. If physicians hold stereotyped views about race that affect their clinical decision-making, the declining diversity of medical student bodies may well have consequences for the quality of medical care. This history of institutional racism on people of color contributes to the mistrust, apprehension, and fear projected toward the entire medical establishment.

Structural Racism

The institutional racism within medical institutions reinforces institutional racism in other sectors, creating a larger system of discrimination, *structural racism*. Structural racism can be described as "the totality of ways in which societies foster racial discrimination via mutually reinforcing systems of housing, education, employment, earnings, benefits, credit, media, healthcare, and criminal justice. These patterns and practices in turn reinforce discriminatory beliefs, values, and distribution of resources, which together affect risk of adverse health outcomes." Institutional racism and structural racism are sometimes used interchangeably, but structural racism refers to overarching patterns beyond a single institution, or even a collection of institutions. Historically, government policies and practices have been largely responsible for the creation of these structures.

De facto and de jure urban residential segregation serves as a case study for how the mechanisms of structural racism operate across multiple sectors and can affect child health and development across the life course. As described in Chapter 2 urban residential racial segregation was reinforced by the practice of **redlining** initiated by the U.S. Federal Housing Administration in 1934. This now illegal (but still covert) practice demarcated urban neighborhoods to be made ineligible for home loans based primarily on the racial composition of the neighborhood. Thus Black neighborhoods were excluded from the federally financed, post-Depression home ownership boom and remained segregated. Through this segregation, existing resources were systematically removed *(disinvestment)* and led to further impoverished communities of color.

The effects of residential segregation were not restricted to the banking or housing sectors. **Residential segregation** ties together multiple systems, driving children's access to and quality of healthcare, education, and justice, as follows:

- *Residential segregation and the healthcare system.* Healthcare institutions were explicitly racially segregated by law and inequitably resourced until passage of the 1964 Civil Rights Act. Vestiges of this segregation continue in hospital-level segregation and racial composition by hospital. In addition, institutions that provide mainly for uninsured or underserved residents are often financially unstable, leading to higher risk of closure in disinvested neighborhoods of color. On the provider level, fewer primary care and specialty physicians practice in disinvested, segregated neighborhoods, and those who are present are less likely to participate in Medicaid.
- *Residential segregation and the education system.* Schools have a similar history of racial segregation and, after a brief respite of integration peaking in 1980, the level of segregation now resembles pre–civil rights levels. School segregation is related to high-risk health behaviors. Within these schools and in their neighborhoods, Black children experience disproportionate penalization and criminalization in the educational and criminal justice systems, reinforcing institutional racism in other sectors and other forms of racism. A low-income Black child is much more likely than a low-income White child to live in a segregated neighborhood. The result is that the Black child will face not only the cumulative disadvantage in both family and neighborhood resources and experiences over time but also the initiation of chains of disadvantage during sensitive periods of childhood key for development and adult transition (e.g., early childhood, adolescence).
- *Residential segregation and the criminal justice system.* Incarceration is concentrated in overpoliced and criminalized Black communities. In the NCHS, almost 13% of Black children had a parent imprisoned during their childhood (to age 17 years), compared with about 6% of White children. Parental incarceration—which may start with a traumatic arrest in the home and later disrupt caregiving, create social stigma, deepen financial disadvantage, disconnect parents emotionally from children, and disrupt children's psychologic development—has been independently associated with a higher risk of children's antisocial behavior.

Most notably, experiences directly related to institutional and structural racism, operating through residential segregation (including financial hardship, parental imprisonment, and neighborhood violence), result in higher levels of ACEs for Blacks and Latinos than for Whites. There has been growing, consistent evidence of the lifelong association between ACEs and a range of negative physical and mental health outcomes across the life course.

Structural racism, shown here with the example of residential segregation, affects child health through various direct and indirect, overlapping pathways, including the concentration of dilapidated housing, inferior quality of the social and built environment, exposure to pollutants and toxins, limited access to high-quality primary and secondary education, few well-paying jobs, overpolicing and criminalization, adverse experiences, and limited access to quality healthcare.

OPPORTUNITIES TO ADDRESS RACISM

Racism as a determinant of health has strong empirical support, and there is promising evidence for community-wide approaches to its mitigation. Less is known about effective interventions in clinical settings. Most medical schools and subsequent training will not have prepared practitioners to examine the role of racism in their patients' lives or clinical care settings. Nonetheless, it is reasonable to expect that pediatricians can help address racism and promote racial justice in at least three ways: during individual patient encounters and at their practice sites, as members of institutions that provide medical care and training, and as respected community members.

Clinical Settings

A first step in understanding that racism affects everyone is personally assessing **implicit bias**. Such biases reflect reflexive patterns of thinking, often using racial stereotypes stemming from living in a racially stratified society. The **Project Implicit Race Implicit Association Test** (https://implicit.harvard.edu/implicit/takeatest.html) is available online, and its results are confidential. The purpose of such tests is to create awareness, not apportion blame. Nonetheless, results are usually jarring for all participants, no matter their racial identity, many of whom will uncover negative racial biases of which they were unaware. Such individual assessments may contribute to addressing interpersonal racism as it triggers self-reflection. Further, a growing number of organizations offer training in understanding common behaviors associated with implicit bias, including microaggressions (see later)

and inequitable hiring practices. Recognizing and undoing personal biases as pediatricians requires training to challenge existing thought processes and actions that are often difficult to see. Seeing and undoing personal biases are lifelong endeavors, and progress should be tracked over time.

Pediatricians and other health workers have an entrusted role in families that requires a partnership. Recognizing the strengths of families and valuing their lived experiences of internalized and interpersonal racism as expertise fosters a more collaborative clinical interaction and relationship. This expertise cannot be readily captured by pedagogy or acquired by a pediatrician in training or clinical practice. Such an approach emphasizes respect for the expertise that caregivers bring to raising their child and begins with the presumption that caregivers want to do what is best for the child. By doing this, physicians can form a collaborative relationship, rather than one based on racial stereotypes and blame. Cultural competence is a widespread concept, recognizing that *other cultures* exist that the dominant culture must learn to decode. In contrast, the concept of **cultural humility**, for which training is increasingly available, considers equality among cultures and a partnership approach to differences.

During clinical encounters with children and families, healthcare workers can use their authority to acknowledge racism. Although there is still a gap in evidence on how, when, and what, pediatricians can consider having "The Talk" with their patients who are Black, young adolescent, and male. "The Talk" is the conversation that Black parents typically initiate with their children regarding interactions with police. In doing so, the pediatrician affirms the need for such conversations to promote safety and may provide opportunities to connect families to community resources. For all young children and youth of color, pediatricians should ask patients if they have they been treated unfairly because of their race, recognizing this can be a form of **bullying**. The experience of racism at all levels can be traumatic. Trauma consists of experiences or situations that are emotionally painful and distressing and that overwhelm people's ability to cope, leaving them powerless. Pediatricians must consider adopting trauma-informed care practices that shift the paradigm from, "What is wrong with you?" to "What has happened to you?"

In addition, healthcare providers must strive for **structural competency**, which is the "trained ability to discern how a host of issues defined clinically as symptoms, attitudes, or diseases also represent the downstream implications of a number of upstream decisions," according to Johnathan M. Metzl and Helena Hansen. Consequently, it is helpful to ensure that clinical practices are aware of other social services that may enhance health and engagement with clinical care, such as a need for legal counsel to address substandard housing, counter landlord harassment, or negotiate threatened evictions (http://medical-legalpartnership.org/), or the support of literacy by prescribing or distributing children's books in order to encourage parents to read to children (http://www.reachoutandread.org/).

Institutional Settings

The healthcare institution more broadly is also a setting where racial dynamics occur. Introducing conversations about race may uncover experiences that would not otherwise be apparent. A common outcome of implicit racial bias is **microaggressions**, actions and attitudes that may seem trivial or unimportant to the perpetrators but create a cumulative burden for those who perceive them. A physician of color might be asked for identification on entering a hospital, whereas White colleagues are not so queried. These microaggressions occur in interactions among staff and with patients and may contribute to an unspoken and uncomfortable racial climate. Although such interactions rarely would violate federal discrimination standards, interaction between coworkers shapes an entire practice and can be perceived by families.

Encouraging institutions to assess the impact of race among patients and staff is a first step. Healthcare delivery institutional settings can use both data and patient accounts to examine racial effects in the practice and experience by routinely disaggregating assessment measures by race/ethnicity. Patient-reported satisfaction or quality of care might be disaggregated by race. In addition, it is important to consider racial equity within the practice's employment structure: Are there discrepancies in hiring, retention, and salaries by race? Are there proper supervision and grievance procedures, particularly around issues related to racial microaggressions? Also, consider the images and language used to discuss and represent both patients and staff, particularly when alluding to race/ethnicity. Organizations such as **Race Forward** (https://www.raceforward.org) and organizational assessment tools developed by the **Race Matters Institute** can help guide institutional assessments and internal change processes. Several local health departments have already incorporated antiracism training into staff professional development and introduced internal reforms to drive organizational change. Because institutional reform is closely associated with other models of productive practices, including quality improvement, collective impact, community engagement, and community mobilization, application of an antiracism lens should be judged by its contributions to organizational effectiveness and on its moral merits.

Education or training institutions have a special role in ensuring a workforce that is both diverse and informed. Patterns of student admissions should be scrutinized, as should the curriculum. The recruitment of Black healthcare workers will enhance the benefits of racially concordant care between Black providers and patients.

Although many medical schools now include diversity training and provide instruction on cultural competency, such instruction is often brief (and sometimes delivered online). By contrast, approaches based on structural competency, cultural humility (see Chapter 12), and **cultural safety** have been implemented in health professionals' training in such countries as Canada and New Zealand. These approaches emphasize the value of gaining knowledge about structural racism, internalized scripts of racial superiority and inferiority, and the cultural and power contexts of health professionals and their patients or clients. Health professionals benefit from the scholarship of diverse disciplines about the origins and perpetuation of, and remedies to counter, racism. Finding class time for these topics encounters a *biomedical bias* that is widespread in medical education, although arguably successful medical practice also requires a host of skills in addition to a firm grounding in pathophysiology and recommended treatments. Racism results in damaging disparities that cause ill health and shorten lives, which justifies the teaching hours committed to its understanding.

Pediatricians as Advocates for Antiracist Practices and Systems

Physicians are respected members of communities and wield the power, privilege, and responsibility for dismantling structural racism. A conceptual review of structural racism highlights the promise of place-based interventions that target geographically defined communities, to engage residents and a range of institutions (across sectors) in order to ensure equitable access to resources and services, remediating the processes set in motion decades earlier. Clinicians play a role in advocating with the halls of medicine in linking patients to services, programming, and other resources and advocating for responsiveness in addressing gaps. Over time, concentrated efforts across sectors in targeted areas have shown improvement in a host of social outcomes, including health outcomes. Similarly, providing access to higher-quality housing, either with housing vouchers or housing lotteries, had unexpected positive health impacts. These findings are encouraging, as are the social policy interventions and systemic change, including legislation such as the Civil Rights Act, the advent of Medicare and Medicaid, and tenement regulations, associated with the narrowing of racial gaps.

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Chapter 3

Global Child Health

Suzinne Pak-Gorstein, Ruth W. Nduati, Sansanee S. Craig, and Susan Wamithi

GLOBAL BURDEN AND TRENDS IN CHILD HEALTH

The **under-5 mortality rate (U5MR)**, also known as the **child mortality rate**, serves as a reliable gauge of child well-being. It measures the outcome of a country's health system and reflects a nation's social and economic development. The global U5MR fell by 61% between the years 1990 and 2020. Despite these gains, in 2019 an estimated *5.3 million children under 5 years of age died worldwide,* which is equivalent to 37.1 *deaths per 1,000 live births,* or nearly *13,700 child deaths each day*. The burden of the world's child mortality disproportionately falls upon low- and middle-income populations of Africa and Asia (Fig. 3.1), with 82% of all child deaths in the world occurring in just two regions: sub-Saharan Africa (55%) and South Asia (27%), compared to the less than 1% of child deaths occurring in high-income countries (HICs). Consequently, a child born in sub-Saharan Africa is over 15 times more likely to die by age 5 years compared to a child born in an HIC.

Improvements in child mortality have been uneven globally, regionally, and nationally. Significant disparities in child mortality persist and are concentrated in specific regions of Africa and Asia. The countries with the highest child mortality gap between the richest and the poorest in 2019 were Nigeria, Guinea, and the Central African Republic. In Nigeria in 2019 while the national rate of child mortality was 117 deaths per 1,000 live births, at the subnational level, the rates ranged from 58 to 261 deaths per 1,000 live births.

Although the number of child deaths has decreased dramatically over the past 3 decades, the early years of life remain one of a child's most vulnerable periods. Among the under-5 child deaths, nearly half occurred within their first month of life (2.4 million deaths in 2019). This estimate of **neonatal deaths** (<1 month of age) translates into 17.9 per 1,000 live births. Declines in neonatal mortality occurred at slower rates, so that in 2019 the neonatal deaths made up 48% of all under-5 deaths (Fig. 3.2).

Neonatal deaths account for a smaller percentage of child mortality in low- and middle-income countries (LMICs) compared to HICs (Fig. 3.3), but the absolute risk of death remains significantly higher. A child in sub-Saharan Africa or in Southern Asia is nine times more likely to die in the first month of life than a child born in an HIC.

An estimated 2 million **stillborn** deaths (≥28 completed weeks' gestation) burden families worldwide every year, which correlates to 13.9 deaths per 1,000 births. This translates into a stillborn baby

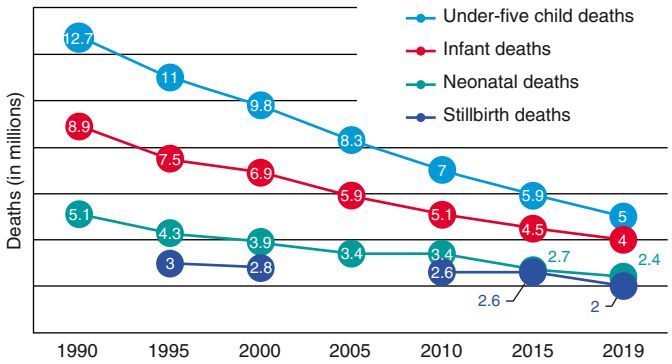

Fig. 3.2 Deaths for under-5 children, infants, neonates, and stillbirths between 1990 and 2019. (*Data from United Nations Inter-agency Group for Child Mortality Estimation – UN IGME 2020; Stillbirth estimates for 1995 and 2009 from Cousens 2011 [2010 rate is from 2009]; year 2000 rates from Lawn 2012, and 2015 rate of 2.6 million is from Blencowe 2016.*)

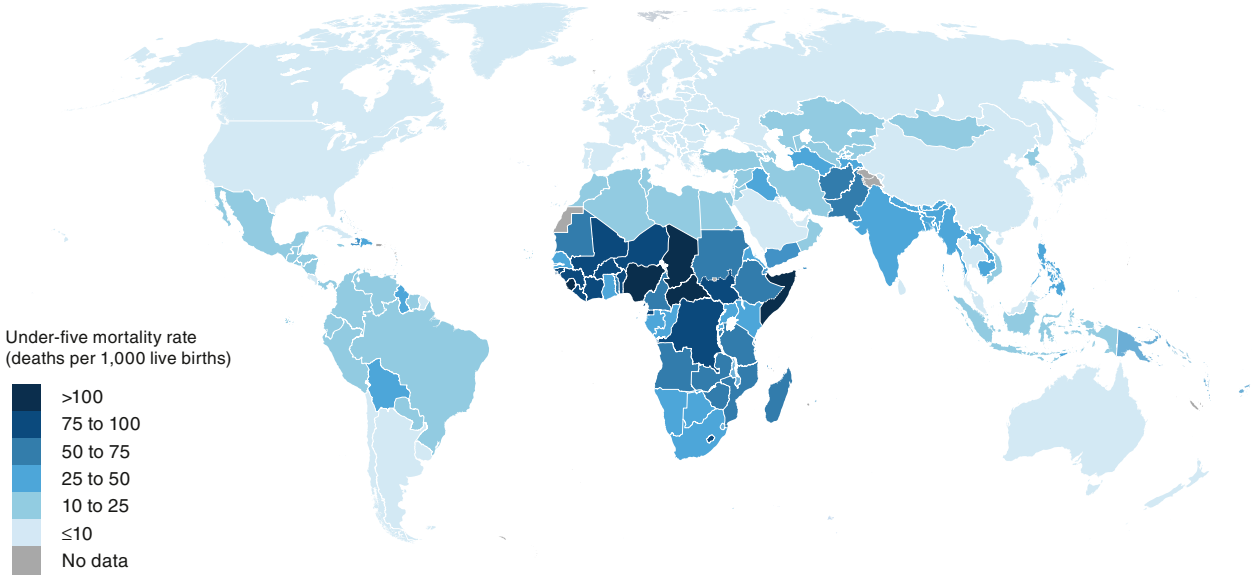

Fig. 3.1 Under-5 mortality rate (probability of dying by age 5 per 1,000 live births) by country, 2019. Note: The classification is based on unrounded numbers. This map does not reflect a position by UN IGME agencies on the legal status of any country or territory or the delimitation of any frontiers. (*From United Nations Inter-agency Group for Child Mortality Estimation [UN IGME]. Levels & Trends in Child Mortality: Report 2020, Estimates developed by the United Nations Inter-agency Group for Child Mortality Estimation. New York: United Nations Children's Fund, 2020. https://www.un.org/development/desa/pd/sites/www.un.org.development.desa.pd/files/unpd_2020_levels-and-trends-in-child-mortality-igme-.pdf.*)

for every 72 births, or one every 16 seconds. These figures are likely an underestimate because stillbirths are underreported, reflecting the low prioritization of this vulnerable age group. Before 2006, no organization published global, regional, or country-specific stillbirth rates. Progress to reduce stillbirths has been slow, with the annual rate of reduction estimated to be half that for neonatal deaths between 2000 and 2019. Almost all stillbirths occur in LMICs (98%), with three-quarters in sub-Saharan Africa and South Asia.

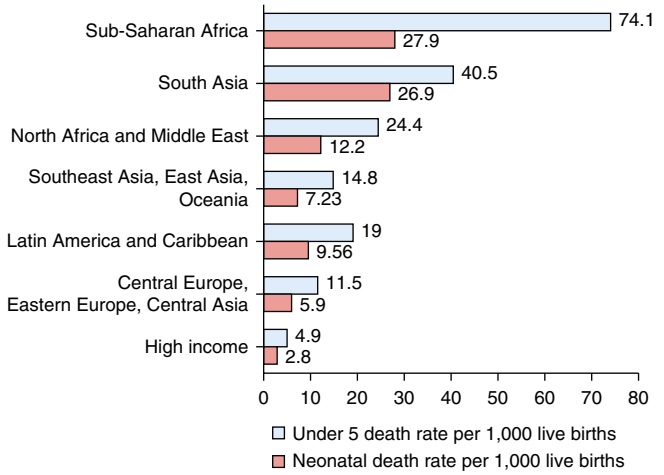

Fig. 3.3 Under-5 child and neonatal death rates per 1,000 live births, 2019. (*Data from GBD 2019 Under-5 Mortality Collaborators. Global, regional, and national progress towards Sustainable Development Goal 3.2 for neonatal and child health: All-cause and cause-specific mortality findings from the Global Burden of Disease Study 2019.* Lancet. *2021;398:870–905.*)

Most childhood deaths are caused by conditions that could be prevented or managed through improved access to simple, low-cost interventions. The **most common causes of child death** are preterm birth complications, intrapartum-related events, pneumonia, and diarrhea (Fig. 3.4). Of all under-5 child deaths, 2.61 million were the result of infectious diseases and 21.7% of all child deaths were vaccine-preventable. **Neonatal disorders** accounted for an estimated 46% of the deaths in children younger than the age of 5 years. In contrast, child deaths from infections in developed countries are less common, where injuries and congenital malformations account for higher proportions of under-5 deaths. **Undernutrition**, including fetal growth restriction, stunting and wasting, and micronutrient deficiencies, contributes up to 45% of under-5 deaths and poor childhood development in LMICs. Undernutrition has an enormous impact on child mortality because of the vicious cycle between nutrition and infection whereby lowered immunity and mucosal damage from inadequate dietary intake lead to increased susceptibility to pathogen invasion, while recurrent illnesses impair the child's appetite and ability to absorb adequate calories and nutrients. In addition, undernutrition early in life can have long-lasting consequences, including impaired cognitive ability and reduced school and work performance.

Infants who start out life with a **low birthweight** are at high risk of death, contributing 60–80% of all neonatal deaths. Most of these

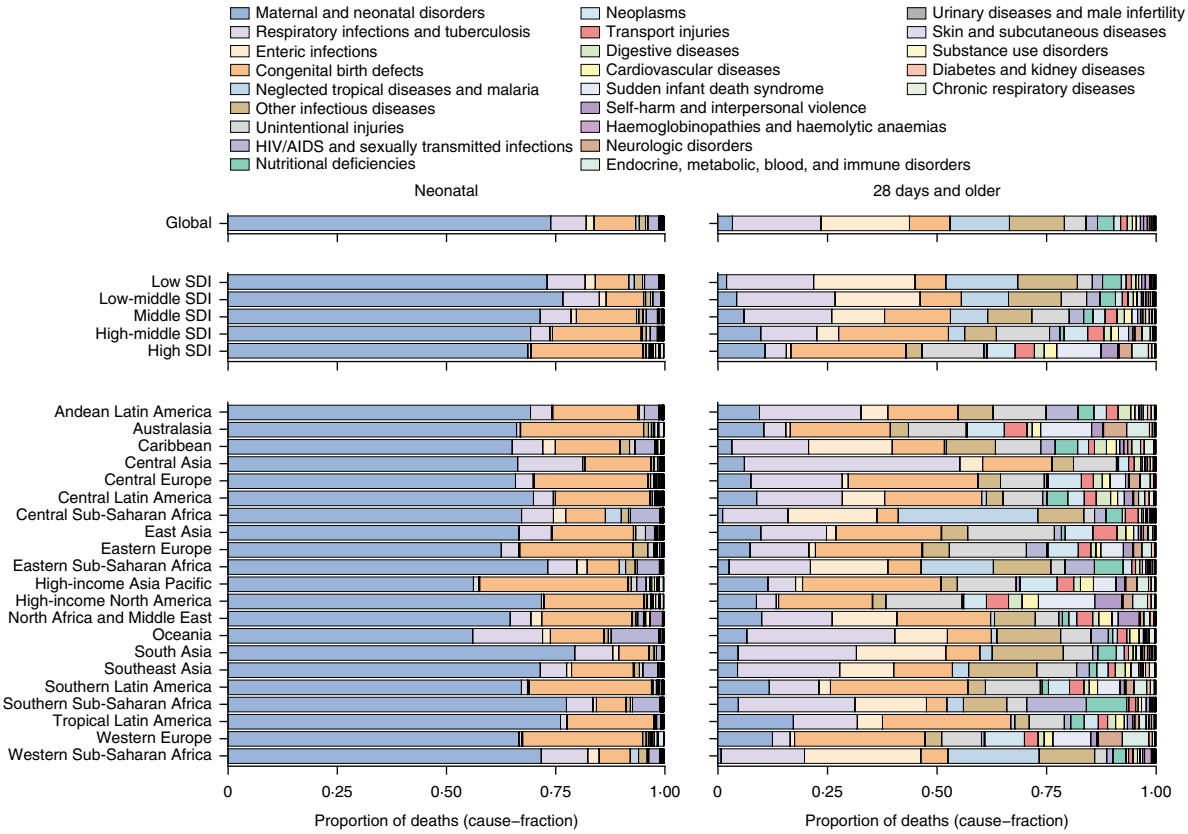

Fig. 3.4 Neonatal and remaining under-5 cause-specific mortality by region and SDI. Values presented are cause fractions: the proportion of total age-specific deaths with a particular underlying cause of death. Causes are presented at Level 2 in the hierarchy, with other noncommunicable diseases disaggregated to include congenital birth defects, sudden infant death syndrome, hemoglobinopathies and hemolytic anemias, endocrine, metabolic, blood, and immune disorders, and urinary diseases and male infertility separately. Total under-5 mortality is split at 28 days to include neonatal (<28 days) separately from children between 28 days and 5 years of age. SDI, Sociodemographic Index. (*From GBD 2019 Under-5 Mortality Collaborators. Global, regional, and national progress towards Sustainable Development Goal 3.2 for neonatal and child health: All-cause and cause-specific mortality findings from the Global Burden of Disease Study 2019.* Lancet *2021;398:870–905. Fig. 3, p. 887.*)

infants are premature (born before 37 weeks of pregnancy) or suffered from fetal growth restriction. About half of **stillbirths** take place during labor, ranging from 10% in developed regions to 59.3% in South Asia, which reflects the role that timely, high-quality care around delivery can play to prevent many deaths.

Mortality among older children age 5-14 is low compared with the younger cohort, although 1 million children in this age group died in 2016, which is equivalent to 3,000 children dying every day. Infectious diseases play a smaller role in deaths among these older children, with injuries from causes such as drowning and road traffic trauma accounting for more than a quarter of the deaths and noncommunicable diseases for about another quarter.

Child health should not be assessed based on mortality rates alone. Children surviving illness are often left with lifelong disabilities, burdening their families and affecting their economic productivity. Approximately 1 in 10 children are born with or acquire a disability, and 80% of these disabled children live in LMICs. Neonatal disorders, infectious diseases, protein-energy and micronutrient deficiencies, hemoglobinopathies, and injuries are leading causes of disability in children. Child deaths can also lead to disability in the surviving mother. For example, a woman who has a stillbirth is at risk of an obstetric fistula or death, with an estimated 78–98% of women with obstetric fistula having had a stillbirth. Also, perinatal loss and child death is a psychologic trauma. Stillbirth, neonatal death, and child loss can lead to posttraumatic stress disorder, depression, anxiety, guilt, and in some settings shame and social stigma, particularly in the mother, with significant impact on the health and well-being of the family.

Adolescents age 10-19 years who have benefited from the gains in child survival grow up to find themselves in social settings where less attention and fewer resources are devoted to their well-being compared to their earlier years of growth. The paucity of support during this time of transition into adulthood diminishes the impact that child survival can have on their lives. *Adolescents made up 18% of the world's population, approximately 1.8 billion individuals, in 2010, and the adolescent population is expected to increase to over 2 billion in the year 2050.* The vast majority of adolescents, 88%, live in LMICs. In 2050, sub-Saharan Africa is projected to have more adolescents than any other region. Although adolescent mortality rates are far lower than their younger age cohorts, in low-income countries adolescents face a lack of educational and employment opportunities and increased risk of injuries and violence, HIV and AIDS, mental health problems, adolescent marriage, and teenage pregnancy—preventing them from attaining their potential as they transition into adulthood. The decade of adolescence is a critical period when poverty and inequity frequently transfer to the next generation. *The intergenerational transmission of poverty is most apparent among undereducated adolescent females.* In many parts of the world poor teenage females are likely to be married early, risking premature childbearing, higher rates of maternal mortality, and contributing to infant and child undernutrition.

THE SOCIAL DETERMINANTS OF CHILD HEALTH AND THE COVID-19 PANDEMIC

The gross national income level accounts for much of the differences in child mortality rates observed between countries; however, other significant factors affect child health. For example, although the wealth of the United States places it in the 7th position with respect to gross domestic product (GDP) per capita (2022) in the world, the U.S. child mortality rate is ranked 47th in the world, at 6.5 deaths out of 1,000 live births, which is higher than Cuba (5.1), Canada (4.9), the UK (4.3), the Czech Republic (3.2), and Japan (2.5). In addition, *national estimates of mortality mask differences in health status among subpopulations within the same country.* In Burkina Faso, the child mortality rate is 43.7 per 1,000 live births among children born to mothers with no education, whereas it is 16.7 per 1,000 among children born to mothers with at least secondary education. Similarly, in 2016 the child mortality rate in Bolivia was 18.6 per 1,000 live births for children in the highest wealth quintile, whereas it was 55.1 per 1,000 for children living in the lowest quintile.

Child health is influenced by socioeconomic factors that operate at multiple levels of society. Disparities in these socioeconomic factors translate into child health inequities as reflected by high rates of disease, poor nutrition, and disability. The immediate, underlying, and basic structural determinants of disease, malnutrition, and disability are outlined in Figure 3.5. Preventive and curative medical interventions focus on the immediate causes of poor health; however, inequities in child mortality and morbidity will persist unless the basic and underlying determinants of health are addressed.

Socioeconomic and Political Roots of Disparities in Global Health

The root influences on a child's health often lie in the economic and political environments in which the child is born (see Figs. 3.4 and 3.5). Growth of economies during the first half of the 20th century was associated with dramatic health improvements, with falling mortality rates and rising life expectancy across all regions. However, the second half of the 20th century was characterized by growing disparities in global economies and health between and within many countries. According to the **World Inequality Report** (http://wir2018.wid.world/) between 1980 and 2016 the richest 1% of the world reaped twice as much of the world's income as the poorest 50% of the world (27% of income growth compared with 12%). Although almost all countries report population-level income inequalities, a few such as the United States have seen income disparities at historical proportions. For example, since 1980 the bottom half of Americans captured only 3% of the total growth. Growing income inequalities translate into greater differences in health outcomes, such as life expectancy, between the rich and poor in the United States (Fig. 3.6). More aggressive redistribution of wealth through taxes and transfers, labor protections, and

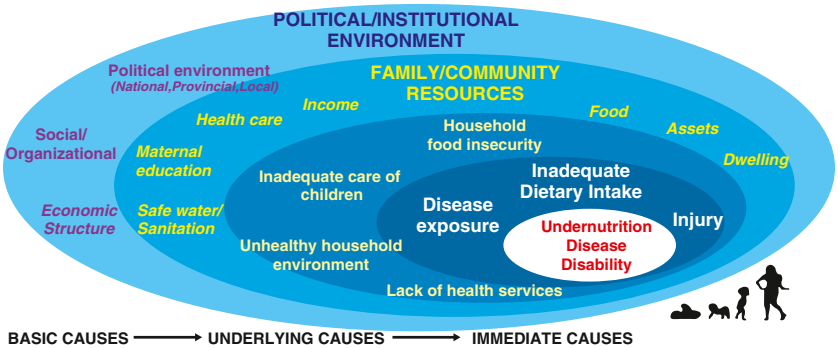

Fig. 3.5 Socioecologic model – Basic, underlying, and immediate determinants of child health.

universal access to education and health care contribute to Europe's significantly lower levels of income disparities.

Evidence supports the notion that inequalities are not just a human rights issue, but are detrimental to economic growth. Wealthier households spend a smaller percentage of their own income, thereby dampening demand and slowing down economies. Poorer households face greater challenges to invest in health and educational opportunities, translating into less human capital and obstacles to be productive and contribute to the economy. In extreme cases, inequalities can threaten social unrest, which further undermines economic activity.

Global disparities have grown between many wealthy and low-income countries, in large part because of **austerity measures**, including structural adjustment programs, imposed on many postcolonial countries by the International Monetary Fund (IMF) and World Bank. To receive loans and pay off their debt, many of these countries were required to take on austerity measures that transformed their economies to produce cash crops and export natural resources to HICs, rather than supporting local industries and investing in human capital and social services. The focus on cash economies rather than health and social service systems limited their ability to provide services to their growing poor population and further hindered responses to the spread of communicable diseases such as HIV/AIDS and the growing prevalence of noncommunicable diseases.

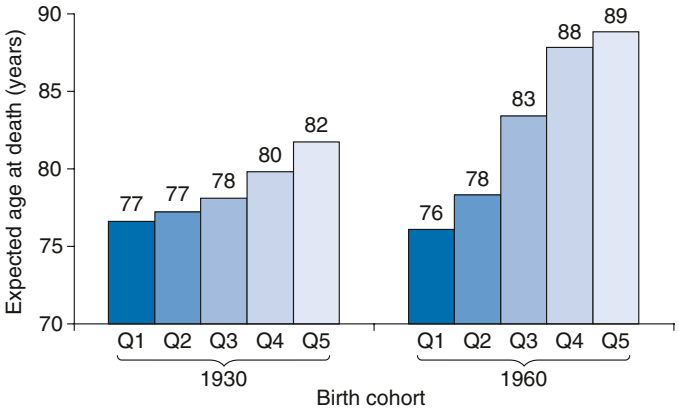

Fig. 3.6 Projected life expectancy for U.S. men at age 50 for 1930 and 1960 birth cohorts by income quintile – Q1 (poorest) to Q5 (richest). (*From Bor J, Cohen GH, Galea S. Population health in an era of rising income inequality: USA, 1980–2015, Lancet. 2017;389:1475–1490, Fig. 5b; with data from National Academies of Sciences, Engineering, and Medicine*. The Growing Gap in Life Expectancy by Income: Implications for Federal Programs and Policy Responses. *Washington, DC: National Academies Press;2015.*)

The COVID-19 Pandemic

The emergence of the severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2) leading to the global pandemic of coronavirus disease 2019 (COVID-19) resulted in over 6 million deaths from COVID-19 and over 499 million cases of COVID-19 infection in the world (see Chapter 311). Children and adolescents tend to experience less severe illness and fewer deaths from SARS-CoV-2 compared to adults, which may lead to lower rates of testing among children and contribute to transmission.

Childhood COVID-19 infections have not affected countries equally, with early evidence showing pediatric deaths from COVID-19 to be significantly greater in LMICs compared to HICs. One study estimated 2.77 pediatric deaths/1 million children in LMICs compared to 1.32/million children in HICs and higher rates of death among infants <1 year of age, at 0.07%, in HICs versus 1.30% in LMICs. Although some LMICs' settings are protected from COVID-19 infection by having a younger demographic profile, lower prevalence of the chronic conditions predisposing to severe infection, and less international transport especially in remote, low-income regions, they also suffer from limited personal protective equipment, poor ventilation of indoor spaces, and inequitable distribution of COVID-19 vaccines. Marginalized groups in these nations who are infected face inadequate medical support and supplies, which can greatly elevate their risk of death and disability. Furthermore, poor availability of testing leads to a large number of deaths and infections being underreported.

The pandemic has significantly strained the already weak health and public health systems in LMICs, raising grave concerns about the risk for youth with chronic conditions. COVID-19 impact has led to disruptions in routine childhood vaccinations, lack of medical supplies, shortages of a health workforce, and reduced delivery of lifesaving services such as cardiac surgery. One estimate showed that 90% of countries report disruptions in essential health services such as essential medicines, routine childhood immunizations, and diagnostics, although some mitigation efforts are in place.

COVID-19 and Social Determinants of Health

COVID-19 affects child and adolescent health indirectly through the rippling effects on the world's economies and disruption of national systems in public health, healthcare, food, and education, all which are feared to be more of a threat than the pandemic itself (Fig. 3.7).

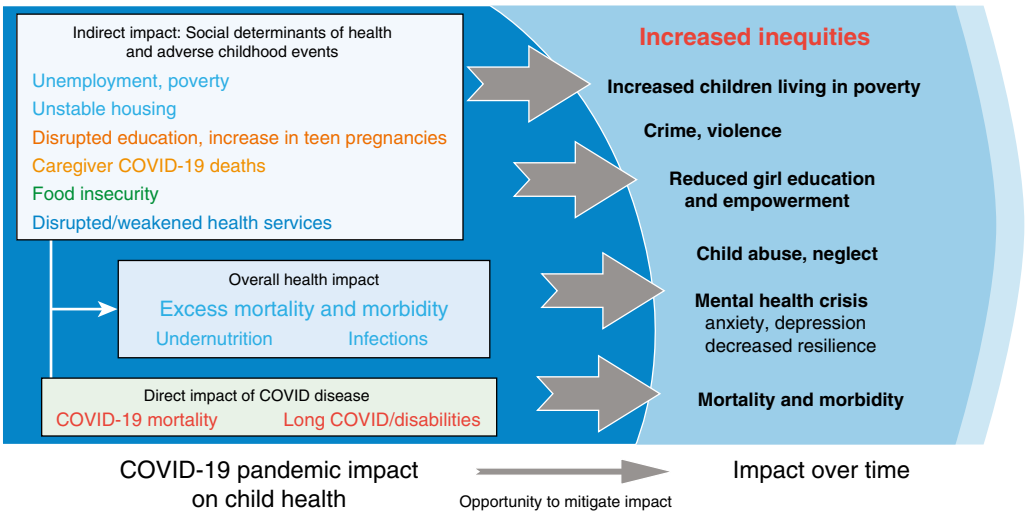

Fig. 3.7 Direct and indirect effects of the COVID-19 pandemic on child and adolescent health over time.

The economic crisis precipitated by the COVID pandemic lockdown and supply chain disruptions places the greatest strain on low-income communities, increasing the proportion of children who live in extreme poverty and face housing instability. An estimated additional 100 million children are estimated to have fallen into extreme poverty worldwide, which is the first increase in this indicator in 20 years. Pre-existing disparities have widened during the pandemic both within countries and globally between LMICs and HICs.

The COVID pandemic has stressed the social fabric of communities around the world so that the most marginalized and vulnerable bear the brunt of its full impact. Many racial and ethnic minority groups are unequally affected by COVID-19, with significantly higher rates of illness and death from COVID-19. Vulnerable communities that existed before the pandemic living in poverty, those employed in the informal sectors (e.g., street vendors), living within close proximity to others, unable to afford being able to stay safe at home, lacking protective gear at work, and without access to healthcare and health insurance are all at greater risk for COVID-19 infections.

Children in LMICs are particularly vulnerable because of the prolonged shutdown of schools, resulting in loss of education without access to technologic online solutions to engage in the educational curriculum. The loss of safe school environments has also been attributed to further widening gender inequities, and several countries reported a surge in adolescent pregnancies, domestic violence, and child abuse after closures.

Furthermore, the number of children affected by COVID-19–associated orphanhood and caregiver death has been estimated to have increased by 90%. The loss of a mother is associated with increased child mortality, especially when maternal death occurs in the first year of the child's life. In regions where rates of maternal death were already high, the impact of COVID-19 leading to loss of a mother or another caregiver can have devastating impact on the lives of children in the short and long term.

An epidemic of poor mental health has followed the COVID-19 pandemic for parents and their children; as the pandemic has progressed, the prevalence of depression and anxiety symptoms among adolescents has escalated. The impact on mental health is not surprising because of the extraordinary disruption of routines, recreation, family income, peer interaction, and school support. The pandemic further halted mental health services in 93% of countries worldwide as the demand for mental health services increased in settings where online mental health services are not an option.

Sustainable Development Goals

The prioritization and planning of global development and international aid has been guided by international goals. In 2015, world leaders agreed to 17 goals, the **Sustainability Development Goals (SDGs)**, to improve global well-being by 2030 (Fig. 3.8). The SDGs were built on the eight **Millennium Development Goals (MDGs)**, which were concrete, specific, and measurable targets set by the United Nations in 2000 to eradicate poverty, hunger, illiteracy, and disease by 2015.

The SDGs have become even more critical to countries planning for ways to mitigate the future impact of the COVID-19 pandemic on child health, particularly among marginalized communities and LMICs. The SDGs highlight recommended interventions for countries to meet their goals in the setting of the challenges created by the COVID-19 pandemic such as optimizing digital centers to increase access to public services, with an emphasis on targeting solutions for communities with low internet connectivity. There have been setbacks in progress towards meeting the 17 SDGs because of the COVID pandemic, highlighting the need to prioritize programs such as routine immunization services, malaria bed net distribution, family planning, and antenatal care services to prevent further negative impacts on child health.

Fig. 3.8 Sustainable development goals. (*Courtesy United Nations Department of Public Information, 2016. United Nations Sustainable Development Goals website: https://www.un.org/sustainabledevelopment/. The content of this publication has not been approved by the United Nations and does not reflect the views of the United Nations or its officials or Member States.*)

SDG-3 is to ensure healthy lives and promote well-being for all at all ages. It includes health-related subtargets, including to reduce U5MR to 25 deaths per 1,000 live births and neonatal mortality rate to 12 deaths per 1,000 live births by 2030. The other 16 SDGs focus mainly on social and economic determinants and the environment. This reflects an important shift to broaden the global targets to include upstream determinants of health, including health systems, and socioeconomic, gender-based, political, and environmental factors. As a social movement to support sustainable development, the SDGs were founded on the recognition that the world's environment, economic and social development, and human health are interconnected and dependent. The SDGs were formulated with core principles and values for economic development, environmental sustainability, and social inclusion for all.

The **Global Strategy for Women's, Children's and Adolescent's Health 2016–2030** maps out the strategies to achieve the SDGs by centering on the goal of health for all women, children, and adolescents using evidence-based approaches, backed by innovative and sustainable financing mechanisms. An important component of the Global Strategy is the inclusion of adolescents as central to the 2030 Agenda for Sustainable Development. In alignment with the SDGs, the Global Strategy focuses on three pillars of action: (1) **ending preventable deaths** among women, children, and adolescents, (2) **ensuring their health and well-being** by ending malnutrition and ensuring access to family planning, reducing exposure to pollution, and achieving universal health coverage, and (3) **expanding enabling environments** by efforts such as eradicating extreme poverty, ensuring good-quality education, eliminating violence against females, enhancing research and technologic capabilities, and encouraging innovation.

In addition to being much broader in scope, the Global Strategy focuses on equity in that the strategy is meant to apply to all people, including the marginalized and difficult-to-reach populations, in all situations, including during crisis. Health insurance coverage would not be assessed based simply on the national average of coverage but also by how well the increases in coverage benefit all population groups regardless of income or educational level.

EVIDENCE-BASED INTERVENTIONS AND INNOVATIONS TO ADDRESS CHILD HEALTH INEQUITIES

Estimates suggest that most of the 5.6 million annual deaths in children younger than 5 could be averted by increasing implementation of proven low-cost interventions (Table 3.1). Childhood deaths from diarrheal illness and pneumonia can be prevented by simple

Table 3.1 Essential Interventions Across the Continuum of Care to Improve Child Survival

HEALTH AND MULTISECTOR ACTIONS

- Ensuring food security for the family (or mother and child)
- Maternal education
- Safe drinking water and sanitation
- Handwashing with soap
- Reduced household air pollution
- Health education in schools

AGE-SPECIFIC ACTIONS

PREVENTION	TREATMENT
Adolescence and Pre-Pregnancy • Family planning • Preconception care	
Pregnancy • Appropriate care for normal and high-risk pregnancies (maternal tetanus vaccination)	• Antenatal steroids for premature births • Intermittent preventive treatment for malaria

Childbirth
• Maternal intrapartum care and monitoring
• Skilled delivery
  • Thermal care for all newborns
  • Clean cord and skin care
  • Early initiation and exclusive breastfeeding within the first hour
	• Newborn resuscitation (e.g., Healthy Babies Breathe)
	• Premature: Surfactant administration, continuous positive airway pressure (CPAP), treatment of jaundice, feeding support for small/preterm infants
	• Kangaroo mother care

Postnatal Period • Appropriate postnatal visits	• Extra care for small and sick babies (kangaroo mother care, treatment of infection, support for feeding, and management of respiratory complications) • Antibiotics for newborns at risk and for treatment of bacterial infections (PROM, sepsis, meningitis, pneumonia)

Infancy and Childhood
• Exclusive breastfeeding for 6 mo and continued breastfeeding up to at least 2 yr with appropriate complementary feeding from 6 mo
• Monitoring and care for child growth and development
• Routine immunization for childhood diseases
• Micronutrient supplementation, including vitamin A, from 6 mo
• Prevention of childhood diseases
  • Malaria (insecticide-treated bed nets)
  • Pneumonia
  • Diarrhea (rotavirus immunization)
  • Meningitis (meningococcal/Hib/pneumococcal vaccine)
  • Measles (vaccine)
• Prevention of mother-to-child transmission
	• Case management of severe acute malnutrition
	• Management of childhood diseases
	  • Malaria (antimalarials)
	  • Pneumonia (case management, antibiotics)
	  • Diarrhea (ORS, zinc supplement, continued feeding)
	  • Meningitis (case management, antibiotics)
	  • Measles (vitamin A supplement)
	• Comprehensive care of children exposed to or infected with HIV (highly active antiretroviral therapy [HAART])

Data from UNICEF, Were WM, Daelmans B, Bhutta Z, et al. Children's health priorities and interventions. *BMJ*. 2015;351:h4300.

measures such as vaccinations and exclusive breastfeeding until 6 months of age. Deaths related to undernutrition, which predisposes children to infectious diseases, may be prevented by proper infant and young child feeding practices, micronutrient supplementation, and community-based screening and management of malnutrition.

Addressing the SDGs to improve the health of mothers, children, and adolescents takes a **life-course approach**. Figure 3.9 displays estimates of coverage for essential interventions across the continuum of care, indicating the wide range of coverage rates within countries that will need to be addressed if SDGs are to be attained.

Vaccine-Preventable Diseases

Vaccines prevent an estimated 2.5 million deaths per year among children under 5 years of age. One study predicted a reduction in 120 million deaths among children born between 2000 and 2030 with vaccination programs. Yet in 2019 an estimated 1.15 million under-5 deaths were the result of vaccine-preventable diseases, with 99% of these children who died living in LMICs. Top contributors were *Streptococcus pneumoniae* and rotavirus, followed by *Bordetella pertussis,* measles virus, *Haemophilus influenzae* B (Hib), and influenza virus.

The WHO Expanded Program on Immunization (EPI) has resulted in a dramatic reduction in deaths, illness, and disability from many of these diseases, in addition to the near elimination of poliomyelitis. Recommendations for routine immunizations have continued to grow with the development of new vaccines that have demonstrated significant lifesaving potential in industrialized countries (Table 3.2). The vulnerability of these programs was demonstrated during the pandemic as global vaccine coverage dropped from 86% in 2019 to 83% in 2020, with an estimated 23 million under the age of 1 year who did not receive basic vaccines in 2020—the highest number since 2009.

In 2015, 86% of the world's infants were vaccinated with 3 doses of DTP. Although vaccines are very effective in improving child survival, rates of coverage are low in many countries. In 2016, a total of 19.5 million did not receive all routine lifesaving vaccinations, and 90,000 deaths were reported due to measles alone. Lifesaving vaccines are still not available in many countries, but progress has been made to expand availability to new countries every year. The lowest number of wild poliovirus cases were reported in 2016 (37 cases). The significant declines in immunization coverage caused by the COVID-19 pandemic have increased the risk for a resurgence of these vaccine-preventable infections amidst weakened healthcare systems.

Reaching Every Child, Everywhere

Global vaccine organizations aim for universal coverage of immunizations but face challenges within countries to attain this goal. Other lifesaving interventions have met barriers to attaining universal coverage. Oral rehydration therapy has been the evidence-based intervention to prevent dehydration from diarrheal disease since the 1970s, yet only 2 in 5 children under 5 with diarrheal illness receive this treatment. The determinants of whether or not a child receives a lifesaving intervention are multifactorial. Characteristics of a healthcare system, the social attitudes and practices, and political climate affect whether universal coverage can be reached for evidence-based essential interventions. Innovations to strengthen vaccine coverage to reach every child in every district of a country range from programs such as **Reaching Every Child through Quality Improvement (REC-QI)**, using community mapping techniques, to the integration of service delivery mechanisms and strengthening the health system with improved surveillance.

Effective Delivery Strategies: Integrated Management of Childhood Illness

Weak health systems impede the ability of countries to deliver cost-effective interventions and lifesaving health messages for children. Such systems are characterized by insufficient numbers of health workers, low-quality training and supervision, and poorly functioning supply chains. The provision of child health services may focus on a single level such as the health facility, but effective and lasting improvements can only be achieved with the integration of delivery at all levels, such as adequate referrals and follow-up between community, clinic, and health facility. As countries resume health services after the COVID-19 pandemic, an important component will be community-based, lifesaving outreach services such as mass immunization, vitamin A campaigns, and community-based health promotion activities (Fig. 3.10).

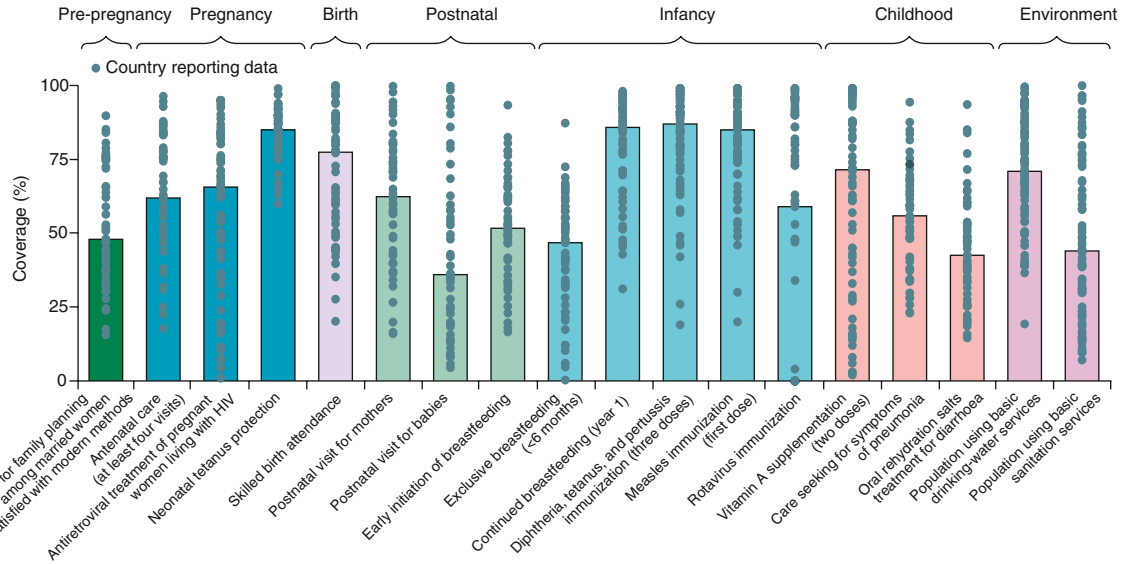

Fig. 3.9 Coverage of interventions across the continuum of care based on the most recent data since 2012 in countdown countries. Bars show median national coverage of interventions, whereas the dots show country-specific data. (*From Countdown to 2030 Collaboration. Countdown to 2030: Tracking progress towards universal coverage for reproductive, maternal, newborn, and child health.* Lancet. *2018;391:1538–1548. Fig. 1.*)

Table 3.2 Routine Childhood Immunizations Recommended by the World Health Organization (2021)*

ANTIGEN		AGE OF 1ST DOSE	DOSES IN PRIMARY SERIES	INTERVAL BETWEEN DOSES		BOOSTER DOSE	CONSIDERATIONS
				1ST TO 2ND	2ND TO 3RD		
BCG		As soon as possible after birth	1				Birth dose and HIV; universal vs selective vaccination; co-administration; vaccination of older age groups; pregnancy
Hepatitis B	Option 1	As soon as possible after birth (<24hr)	3	4 wk (min) with DTPCV1	4 wk (min) with DTPCV2		Premature and low birth weight; co-administration and combination vaccine; high risk groups
	Option 2	As soon as possible after birth High risk groups	4	4 wk (min) with DTPCV1	4 wk (min) with DTPCV2		
Polio	bOPV + IPV "Preferred schedule" (fractional Salk-IPV permitted)	bOPV 6 wk IPV 14 wk	5 (3 bOPV and 2 IPV)	bOPV 4 wk (min) (e.g. with DTPCV2) IPV ≥ 4 mo (min) (e.g. with MCV)	bOPV 4 wk (min) (e.g. with DTPCV3)		bOPV birth dose; type of vaccine; fractional dose IPV; transmission and importation risk; local epidemiology, programmatic implications and feasibility for "early" option
	bOPV+IPV "Early option" (full dose IPV only)	bOPV 6 wk IPV 6 wk	5 (3 bOPV and 2 IPV)	bOPV 4 wk (min) (e.g. with DTPCV2) IPV 14 wk (min) (e.g. with DTPCV3)	bOPV 4 wk (min) (e.g. with DTPCV3)		
	IPV / bOPV Sequential	8 wk (IPV 1st) bOPV (4–8 wk after 2nd IPV)	4 (2 IPV followed by ≥ 2 bOPV)	IPV (4–8 wk)	bOPV (4–8 wk)†		
	IPV-only	6–8 wk	3	4–8 wk	4–8 wk	IPV booster (6 mo after 3rd dose) is needed when 1st dose given at < 8 wk	Only for countries in polio-free regions with a very low risk of importation and sustained high routine immunization coverage (DTP3> 90%)
	Alternative IPV-only (fractional permitted)	≥14 wk	2	≥ 4 mo (e.g. with MCV)			

ANTIGEN		AGE OF 1ST DOSE	DOSES IN PRIMARY SERIES	INTERVAL BETWEEN DOSES		BOOSTER DOSE	CONSIDERATIONS
				1ST TO 2ND	2ND TO 3RD		
DTP-containing vaccine		6 wk (min)	3	4 wk (min) – 8 wk	4 wk (min) – 8 wk	3 boosters 12–23 mo (DTP containing vaccine); 4–7 yr (Td/DT containing vaccine); and 9–15 yr (Td)	Delayed/ interrupted schedule Combination vaccine; Maternal immunization
***Haemophilus influenzae* type b**	Option 1	6 wk (min) 59 mo (max)	3	4 wk (min) with DTPCV2	4 wk (min) with DTPCV3		Single dose if >12 mo of age; not recommended for children > 5 yr; delayed/interrupted schedule; co-administration and combination vaccine
	Option 2		2–3	8 wk (min) if only 2 doses 4 wk (min) if 3 doses	4 wk (min) if 3 doses	At least 6 mo (min) after last dose	
Pneumococcal (conjugate)	Option 1 3p+0	6 wk (min)	3	4 wk (min)	4 wk		Schedule options (3p+0 vs 2p+1);vaccine options; HIV+ and preterm neonate booster; vaccination in older adults
	Option 2 2p+1	6 wk (min)	2	8 wk (min)		9–18 mo	
Rotavirus		6 wk (min) with DTP1	2 or 3 depending on product	4 wk (min) with DTPCV2	For three dose series – 4 week (min) with DTPCV3		Not recommended if >24 mo
Measles		9 or 12 mo (6 mo min)	2	4 wk (min)			Co-administration live vaccines; combination vaccine; HIV early vaccination; pregnancy
Rubella		9 or 12 mo with measles containing vaccine	1				Achieve and sustain 80% coverage; co-administration and combination vaccine; pregnancy
HPV		As soon as possible from 9 yr (females only)	1–2	6–12 mo			Target 9–14 yr old females; off-label 1 dose schedule; MACs with intro; pregnancy; HIV and immunocompromised

*Please see WHO reference for specific vaccine recommendations for children residing in certain regions and in high-risk populations and more detailed footnotes. https://cdn.who.int/media/docs/default-source/immunization/immunization_schedules/table_2_feb_2023_english.pdf?sfvrsn=3e27ab48_11&download=true.

†Interval between 3rd and 4th, bOPV (4–8 wk).

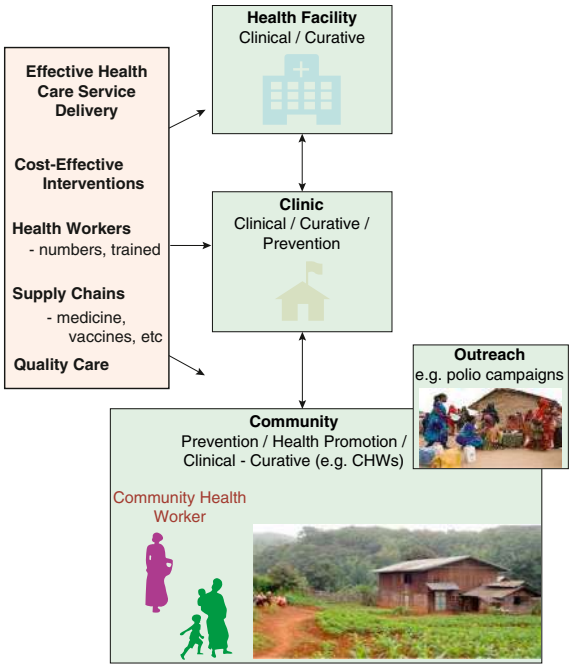

Fig. 3.10 Health services delivery systems.

Community-based interventions are effective in extending healthcare delivery, are low cost, improve healthcare-seeking behavior, and can reduce infant and child mortality and morbidity. They may include **community health workers (CHWs)**, who are members of a community without formal medical training chosen to provide basic health and medical care to their community, as discussed in more detail later.

The lack of integration of programs that deliver individual interventions results in missed opportunities. Children may receive immunizations from one health worker at one encounter, but go somewhere else to obtain oral rehydration solution (ORS) for diarrheal illness and yet elsewhere for treatment of malnutrition. Past programs focused on a single disease and set of interventions, whereas most children present with overlapping signs and symptoms to community-level health facilities with limited diagnostic tools such as laboratories or radiography.

The **Integrated Management of Childhood Illnesses (IMCI)** was launched in the mid-1990s by UNICEF and the World Health Organization (WHO) as an approach to reduce child death, illness, and disability and to promote improved growth and development in countries struggling with high child mortality rates. The IMCI was designed to increase coverage of evidence-based, high-impact interventions that tackle the top causes of child mortality by integrating health promotion, illness prevention, and disease treatment.

The IMCI contains both preventive and curative elements that are set forth through a series of clinical algorithms and guidelines for case management (Fig. 3.11 provides an example) and implemented by families, communities, and providers at health facilities. One key component of the IMCI strategy is to train CHWs to use the algorithms to identify signs of common childhood illness and to decide when a child needs referral to a health facility. IMCI trains CHWs to instruct parents on home management of ill children, including ORS and zinc for diarrhea, antimalarial medicine for febrile children who test positive for malaria, and antibiotics for children with signs of pneumonia. CHWs can schedule follow-up visits for ill children. They also promote use of bed nets, handwashing, and proper infant and young child feeding. In 2003, the IMCI guidelines underwent minor transitions, including the addition of newborn care under 1 week of age, so that it was renamed Integrated Management of Newborn and Childhood Illnesses (IMNCI).

Over 100 countries have adopted the IMNCI and implement some or all of its components that include not only improving health workers' skills but also strengthening health systems and improving family and community practices. After 20 years of implementation, a recent review of the IMNCI strategy noted that it was associated with a 15% reduction in child mortality when activities were properly implemented in health facilities and communities. However, the implementation of IMNCI was found to be uneven between and within countries. In many countries the resources for CHW training and supervision, supply of medications, and referrals were limited or absent. The IMNCI was only successful in those countries with strong government leadership and a commitment to implement IMNCI in partnership with support from groups such as UNICEF and the WHO. The success of IMNCI required an adequate health system and a systematic approach to planning and implementation.

Social Protection Programs: Conditional and Unconditional Cash Transfers

Financial incentives are widely used to improve healthcare coverage, alleviate poverty, and improve access to child health services. In industrialized countries, cash transfers are a common mechanism for ensuring that the poorest, most marginalized subgroups of the population, particularly with children, receive adequate support to meet their basic needs. Before the COVID-19 pandemic, cash transfer schemes were increasingly being used in LMICs to support population needs, and COVID-19 led to an enormous elevation of social protection efforts as a critical response to mitigate the far-reaching impact of the pandemic on vulnerable communities. Many lessons have been learned during this escalation of social protection programs, which provides hope for continued support of families in need, in addition to an expansion of services to mitigate the projected increases in children living in extreme poverty.

Out-of-pocket expenses by households form the major share of total health expenditure in most LMICs. Many social protection programs serve a dual purpose of reducing financial barriers and strengthening service delivery. Financial incentives may include cash transfers, microcredit, vouchers, and user fee removal and health insurances. **Financial incentive programs may be unconditional**, provided to eligible families without any requirements or expectations, based on the belief that families will use this type of financial support for their children's best interests. **Other incentives are conditional on health promotion behavior targeting child health**, such as the provision of cash or vouchers only to those families who participate in mother groups to learn about breastfeeding practices, visiting clinics for child vaccinations and growth monitoring, engaging in deworming, and ensuring that their children receive vitamin A and iron supplementation. Some social protection programs are also directed towards educational improvement by making cash transfers conditional on child school enrollment, attendance, and occasionally on some measure of academic performance.

Expansions of innovations that have been scaled up quickly during the pandemic protected millions of families such as through mobile cash transfer programs that take advantage of data and technology to better target those in need. Certain countries with a large proportion of children at risk are projected to have a protracted recovery period. Efforts have been taken to identify and provide international support for these countries and communities (Fig. 3.12).

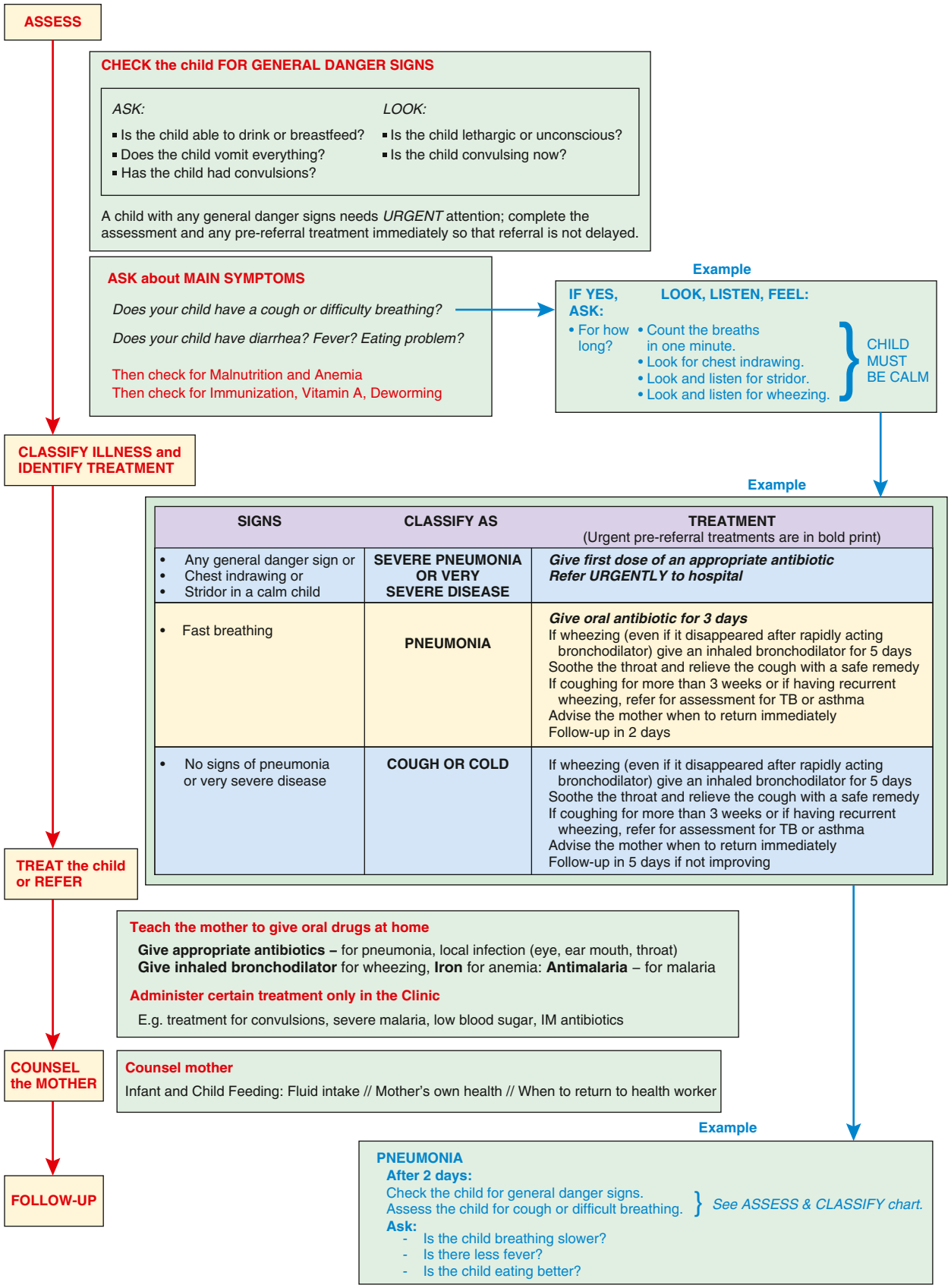

Fig. 3.11 Integrated management of childhood illnesses (IMCI) Generic IMCI table for appraisal of respiratory symptoms, with each algorithm tailored to the specific country context before implementation.

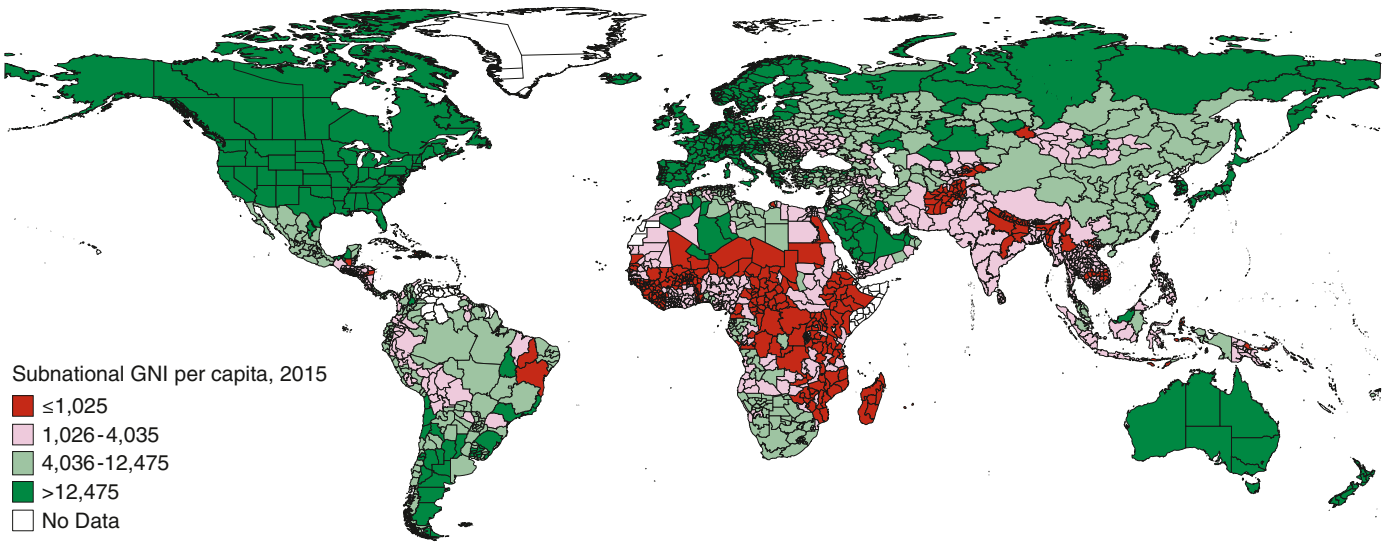

Fig. 3.12 Subnational poverty "hotspots" for extreme poverty (2015), based on GNI per capita. (*From Desai R, Kharas H, Ozdogan S. Poverty hotspots and the correlates of subnational development.* Brookings Institution. *Dec. 2020. Global working paper #149. https://www.brookings.edu/wp-content/uploads/2020/12/Poverty-hotspots_final.pdf.*)

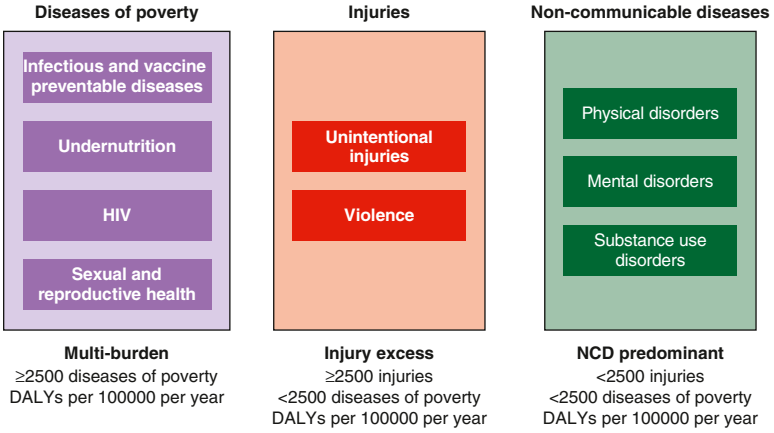

Fig. 3.13 Country categorization based on adolescent burden of disease. Categorization into 3 groups according to adolescent burden of disease and reflecting passage through epidemiologic transition. DALYs, Disability-adjusted life-years; NCD, noncommunicable diseases. (*From Patton GC, Sawyer SM, Santelli JS, et al. Our future: A Lancet commission on adolescent health and wellbeing.* Lancet. *2016;387:2423–2478, Fig. 7.*)

CHALLENGES IN GLOBAL HEALTH

Adolescent health. The Global Strategy, which directs countries to attain their SDGs, has called upon countries to focus efforts to support adolescent health given the potential role in breaking the intergenerational cycle of poverty. One challenge to attaining these health goals will be to effectively advocate for governments to invest in this age group as a means to improve national productivity and the economy. Considerable gaps in data on adolescents pose one of the biggest challenges to promoting their health and their rights. Data on early adolescents age 10-14 is relatively scarce, thus limiting the knowledge of this crucial period. Efforts to promote youth participation in delineating their health priorities are essential to the design of effective interventions.

One critical strategy to support adolescents is to improve completion of secondary school education, particularly among girls. The development of adolescents' capacities and values through education can empower an entire generation to become economically independent, to become positive contributors to society, and to break out of the cycle of poverty.

Other threats to adolescent health include mental health, substance abuse, sexual and reproductive health, and noncommunicable diseases (NCDs) such as obesity, which vary depending on country (Fig. 3.13). The surge in adolescent pregnancies that has been reported in several countries during the COVID-19 pandemic places particular emphasis on the need to strengthen youth access to sexual and reproductive education and services.

A common theme for these threats is that interventions to combat these issues must attempt to influence individual behavior and attitudes while promoting healthy lifestyles. It is estimated that around 20% of the world's adolescents have a mental health or behavioral problem, and this has only increased since the COVID-19 pandemic. Depression is the single largest contributor to the global burden of disease for people age 15-19, and suicide is one of the three leading causes of mortality among people age 15-35. Efforts to tackle these problems will require an interdisciplinary approach, with more research needed to identify and evaluate interventions to effectively influence adolescent behavior in LMIC settings.

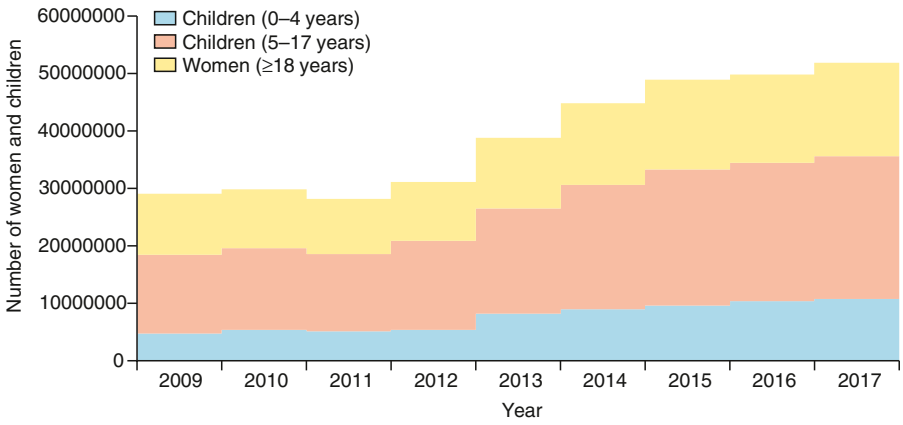

Fig. 3.14 Estimated number of children and women displaced by conflict, 2009–2017. (*From Bendavid E, Boerma T, Akseer N, et al. The effects of armed conflict on the health of women and children.* Lancet. *2021;397:522–530, Fig. 2, p. 524.*)

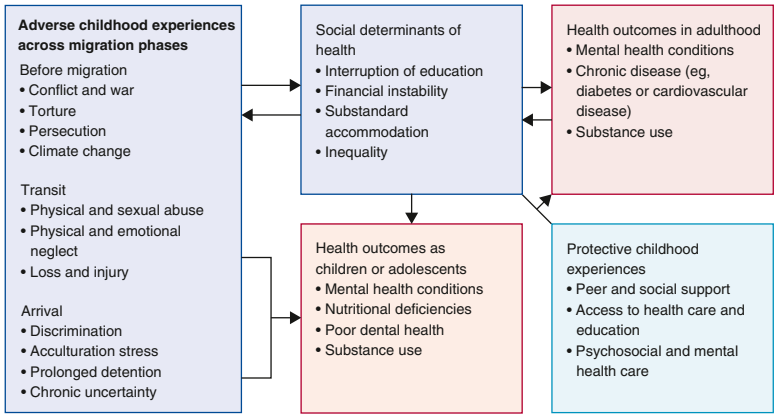

Fig. 3.15 Intersection between adverse childhood experiences during migration and social determinants of health and their long-term effects. Protective childhood experiences can act as a buffer so that adverse health conditions of childhood and adolescence are less prolonged and less severe in adulthood. (*From Maioli SC, Bhabbha J, Wickramage K, et al. International migration of unaccompanied minors: Trends, health risks, and legal protection.* Lancet Child Adolescent. *2021;5:882–895.*)

Climate change. Climate change is the most urgent and alarming long-term threat to child health and well-being in this century. Contributing to environmental degradation, the loss of natural resources and change in climate undermine food and water sources. Climate change and an increased frequency and severity of humanitarian crises have already adversely affected children's health and nutrition. Advocacy at local, national, and international levels to reduce greenhouse gas emissions are needed.

Conflict, emergency situations, and migration. During times of crisis, children, adolescents, and women are most vulnerable (Fig. 3.14). Although the youngest are the most likely to perish because of disease or injuries, all children suffer as a result of food shortages, poor water and sanitation, interrupted education, and family separation or displacement. Approximately 281 million migrants live outside their countries of birth, which includes 35 million young children and adolescents under the age of 20 who have migrated either with their parents or are unaccompanied. Many other children are affected by migration through parental separation because of deportation or emigration.

Children and adolescents crossing borders are often not entitled to the same protections and rights as those who reside in a given country, leaving them at greater risk of discrimination and exploitation. A rights-based approach to migration is required to reinforce the steady buildup of support and attention to migration issues at the international and national levels. This approach must also address the long-term social and health consequences and the root causes of migration (e.g., instability, inequality, discrimination, poverty) in the country of origin and should incorporate policies specifically targeted for young children, adolescents, young women, and vulnerable populations, including those left behind when family members migrate away (Fig. 3.15).

Health information and communications technology. The widespread proliferation of health information and communications technology (HICT) has transformed health care. Social media and mobile apps can be used to raise awareness and build skills, especially in LMICs, where other channels of public health messages may not be readily accessible.

The dissemination of HICT has not been equitable. The majority of LMICs are still in the early stages of adoption. Many healthcare settings in LMICs rely exclusively on paper-based records or simple electronic data-capture tools such as spreadsheets for disease surveillance, reporting, and research. Barriers to implementing HICT in LMICs include lack of health data infrastructures, reliable internet and electricity, workforce training, tools that fit local healthcare needs and culture, and sustainable funding. A further challenge is the need to ensure privacy and security while standardizing the format in which health data are captured to permit sharing of health information across facilities to reduce costly inefficiencies and to improve quality of care. Balanced partnerships between health care and technology communities across low-, middle-, and high-income countries are needed to share knowledge, foster innovation, and strengthen health information systems to advance equitable health outcomes.

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Chapter 4

Quality and Value in Healthcare for Children

Trisha L. Marshall, Amanda C. Schondelmeyer, and Jeffrey M. Simmons

THE NEED FOR IMPROVEMENT IN QUALITY AND VALUE

Adults and children receive recommended evidence-based care only about half the time. The gap between knowledge and practice widens to a *chasm* in part because of variations in practice and disparities in care from doctor to doctor, institution to institution, geographic region to geographic region, and socioeconomic group to socioeconomic group. Furthermore, it is estimated that it routinely takes more than a decade for new knowledge to be adopted into clinical practice.

In addition to appropriate care that patients do not receive, the U.S. healthcare systems also deliver much care that is unnecessary and waste many resources in doing so. This overuse or waste is one **key driver** of the disproportionate costs of care in the United States compared with other developed countries' delivery systems (in 2016, the United States spent about twice as much per capita, adjusting for gross domestic product [GDP], on healthcare compared to the average of peer wealthy nations). It is estimated that more than one quarter of all U.S. healthcare spending is waste. Gaps in appropriate care, combined with overuse and high costs, have driven conversations about the need to improve the value of care, which would mean better quality at lower overall costs. **Choosing Wisely**, an initiative initially sponsored by the American Board of Internal Medicine Foundation and subsequently endorsed by the American Academy of Pediatrics (AAP), asked medical societies to identify overused practices that clinicians could then make collective efforts to address.

WHAT ARE QUALITY AND VALUE?

The National Academy of Medicine (NAM) defines *quality* of healthcare as "the degree to which healthcare services for individuals and populations increases the likelihood of desired health outcomes and are consistent with current professional knowledge." To measure healthcare quality, they identified *Six Dimensions of Quality*: **effectiveness**, **efficiency**, **equity**, **timeliness**, **patient safety**, and **patient-centered care**. Healthcare services need to be *effective,* which means that they should result in benefits and be grounded in evidence whenever possible. Healthcare services also need to be *efficient,* which incorporates the idea of avoiding waste and improving system cost efficiencies, and the services should be *safe* for patients. Healthcare services must be *timely,* thus incorporating the need for appropriate access to care (see Chapter 5). Healthcare services should be *equitable,* which highlights the importance of minimizing variations as a result of race, ethnicity, gender, geographic location, and socioeconomic status (SES). Healthcare quality should be *patient centered,* which underscores the importance of identifying and incorporating individual patient needs, preferences, and values in clinical decision-making. In pediatrics, the patient-centered dimension extends to family-centeredness, so that the needs, preferences, and values of parents and other child caregivers are considered in care decisions and system design.

This framework emphasizes the concept that all Six Dimensions of Quality need to be met for the provision of *high-quality* healthcare. Collectively, the Six Dimensions of Quality represent *quality* in the overall *value* proposition of quality per cost. Value remains a critical concept, though difficult to measure accurately.

The evolving healthcare system requires physicians, healthcare providers, hospitals, and healthcare organizations to partner together and with patients to define, measure, and improve the overall quality and value of care delivered. Concrete examples of the evolving U.S. perspective include the widespread adoption of **Maintenance of Certification** (MOC) requirements by medical-certifying bodies, which require providers to engage in activities that improve care in their practices, and the core quality measurement features and population health incentives of the **Patient Protection and Affordable Care Act (ACA)** of 2010. The ACA also established the **Patient-Centered Outcomes Research Institute (PCORI)** to develop a portfolio of effectiveness and implementation research that requires direct engagement of patients and families to partner in setting research priorities, formulating research questions, and designing studies that will directly affect the needs of patients to improve the value of the research.

Although significant progress has been made along many dimensions of quality, a notable gap is the lack of progress on addressing inequities in healthcare. Disparities in healthcare based on racial or ethnic background, SES, and for patients and families with limited English proficiency are well documented and include inequities in access to care, treatment of pain, and in number of adverse events experienced during acute hospitalizations (see Chapter 2).

FRAMEWORKS FOR QUALITY IMPROVEMENT

Quality improvement (QI) science is a predominant method used to close gaps and improve value. Initially focused on improving performance and reliability in care processes, more recently, in part inspired by the Institute for Healthcare Improvement's **Triple Aim** approach, QI is also being used to improve value for *populations* of patients by focusing more on *outcomes* defined by patients' needs. The Triple Aim included (1) improving the patient experience of care, (2) improving the health of populations, and (3) reducing per capita cost of healthcare. The **Quadruple Aim** approach adds the fourth dimension of healthcare worker experience, or *joy in work,* to focus delivery systems on the need to consider the resilience and safety of the clinical workforce in order to maintain the delivery of high-value care.

Quality is broader in scope than QI. Many quality measurement systems have attempted to be more transparent with clinicians and patients about costs of care. Because more direct costs have been shifted to patients and families through widespread adoption of high-deductible insurance plans (i.e., families experience lower upfront insurance coverage costs but pay for certain acute healthcare expenses out-of-pocket until the preset deductible is met), better awareness of costs has become a more important driver of improvement in value, in part by reducing overuse.

The applied science of QI currently in use in healthcare is also firmly grounded in the classic scientific method of observation, hypothesis, and planned experimentation. There are four key features of the applied science of QI: appreciation of systems, understanding variation, knowledge theory, and psychology of change. In addition to this theoretical framework, statistical analytic techniques have evolved to better evaluate variable systems over time. Although each derives key features from this applied scientific foundation, multiple QI methodologies are currently in use in healthcare. At their most parsimonious level, each method can be described as a three-step model: *Data → Information → Improvement.* Quality needs to be measured. Data obtained from measurement needs to be converted into meaningful information that can be analyzed, compared, and reported. Information must then be *actionable* to achieve improvements in clinical practice and health systems' processes. Some common approaches to conducting QI in healthcare, many of which originated in manufacturing, include Model for Improvement, Six Sigma, and Lean methodologies. These approaches are not mutually exclusive and share common features and tools. The Model for Improvement is an overarching framework

for improvement. Six Sigma focuses largely on reducing variation in processes, and Lean focuses on eliminating waste.

Model for Improvement

The Model for Improvement is structured around three key questions: (1) What are we trying to accomplish? (2) How will we know that a change is an improvement? and (3) What change can we make that will result in improvement? Clarifying the first question, the *goal,* is critical and is often a step skipped by clinicians, who typically already have change ideas in mind. The second question is about defining measures, with an emphasis on practicality and efficiency. The third question is about defining testable ideas for improvement, which are subsequently tested using a framework of rapid cycle improvement, also known as the **plan-do-study-act (PDSA) cycle** (Fig. 4.1A). The PDSA cycle is typically aimed at testing small care process changes in iterative, rapid cycles. After discrete testing periods, results are analyzed, and the next cycle of change testing is planned and implemented (i.e., multiple PDSA cycles, often called a PDSA *ramp,* build on previous learning from PDSAs; see Fig. 4.1B). Valuable information can be obtained from PDSA cycles that are successful, and those that are not, to help plan the next iteration of the PDSA cycle. The PDSA cycle specifically requires that improvements be data driven. Many clinicians attempt to make changes for improvement in their practice based on clinical intuition rather than on interpretation of empirical data. Data can be either quantitative or qualitative in nature.

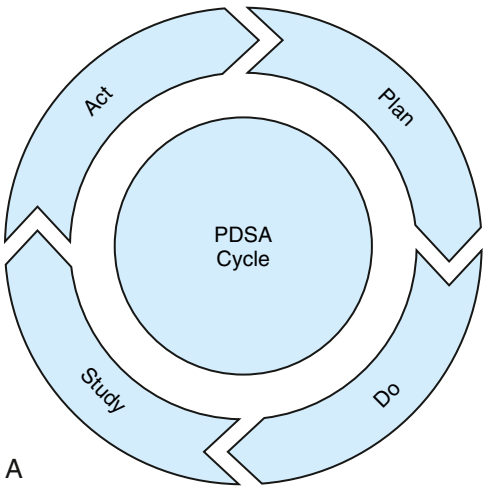
One successful QI collaborative using the Model for Improvement in the outpatient setting is related to improvements in remission rates and reduction in systemic corticosteroid use among children with inflammatory bowel disease (IBD, Crohn disease, or ulcerative colitis). This work was supported by the **ImproveCareNow Network** (https://improvecarenow.org/), a learning health system. A *learning health system* is a collaborative endeavor organized around communities of patients, clinicians, and researchers working together to integrate research with QI (i.e., knowledge dissemination and implementation) to improve care delivery while advancing clinical research. For the IBD network, outpatient gastroenterology practices standardized treatment approaches to align with existing evidence through QI interventions adapted to local circumstances. Therapeutic decisions for individual patients remained at the discretion of physicians and their patients.

Six Sigma

Six Sigma is related to the reduction in *undesirable variation in processes.* Six Sigma attempts to provide a structured approach to unwanted variations in healthcare processes. Six Sigma approaches have been successfully used in healthcare to improve processes in both clinical and nonclinical settings.

Lean Methodology

Lean methodology focuses on reducing waste within a process in a system. Figure 4.2A illustrates the steps in the process of a patient coming to the emergency department (ED). After the initial registration, the patient is seen by a nurse and then the physician. In a busy ED, a patient may need to wait for hours before registration is complete and the patient is placed in the examination room. This wait time is a waste from the perspective of the patient and the family. Incorporating the registration process after placing the patient in the physician examination room can save time and minimize waste (see Fig. 4.2B). Lean methods have been successfully used in several outpatient and inpatient settings with resulting improvements in efficiency. Lean principles have also been adopted as a core strategy for many children's hospitals and health systems with the goal of improving efficiencies, including access, while reducing waste. These efforts can improve aspects of quality while also



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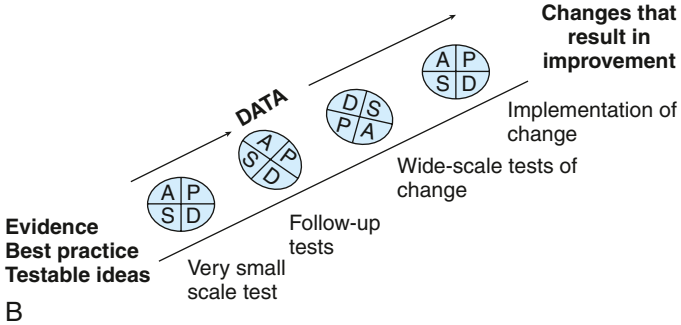

B

Fig. 4.1 A, The plan-do-study-act (PDSA) cycle. B, Use of PDSA cycles: a ramp. (*From Langley GJ. The Improvement Guide: A Practical Guide to Enhancing Organizational Performance. San Francisco: Jossey-Bass:1996. Copyright 1996 by Gerald J. Langley, Kevin M. Nolan, Thomas W. Nolan, L. Norman, and Lloyd P. Provost.)*

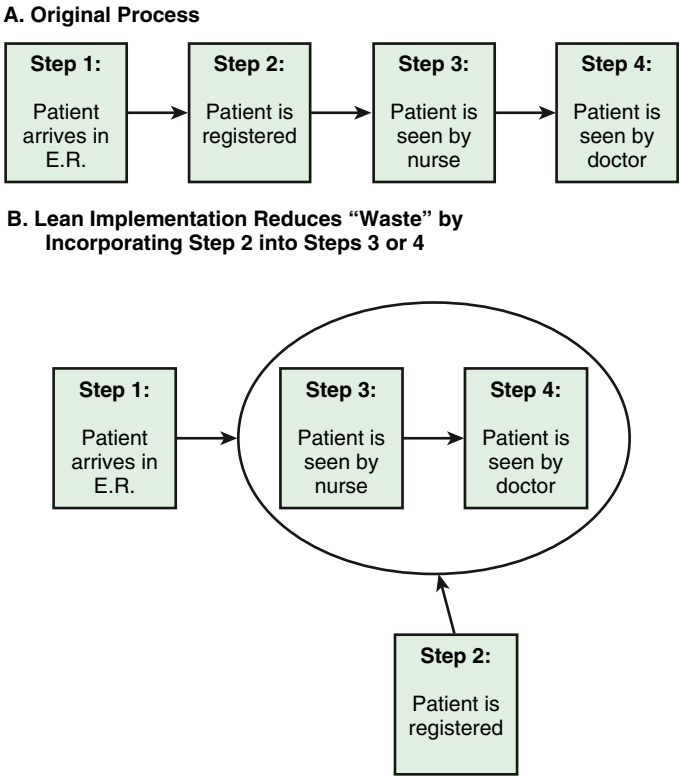

Fig. 4.2 A and B, Lean methodology—waste reduction.

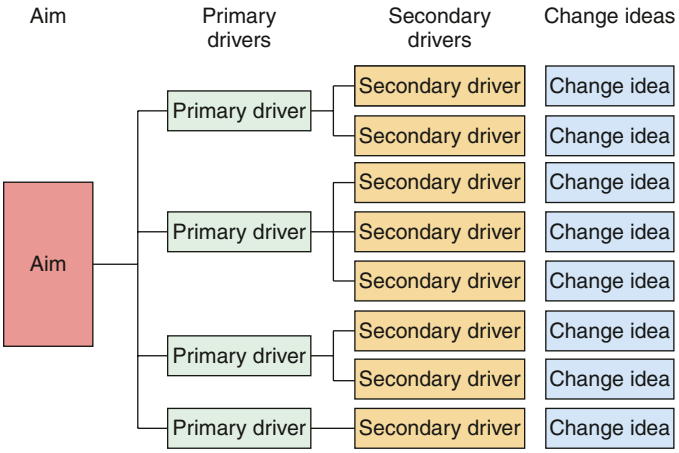

Fig. 4.3 Key driver diagram: theory of how to achieve an aim.

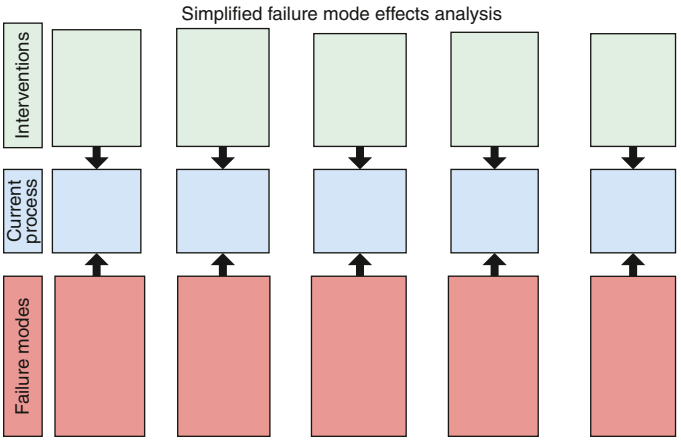

Fig. 4.4 Failure modes and effects analysis (FMEA).

typically reducing costs. Another key principle of Lean methods is the empowerment of the workforce and frontline leaders to make changes that reduce hassles for them and for patients.

Tools for Organizing Quality Improvement Theory and Execution

QI efforts need to be organized around a theory of how the desired changes in outcome will be achieved. Multiple tools are available to help organize a QI team's thinking and execution. These tools typically help teams organize work into discrete projects or phases, and some of them also help teams develop change ideas.

Key driver diagrams (KDDs) are a tool to organize the theory of learning that underpins a QI project (Fig. 4.3), using the Model for Improvement. Important aspects of a KDD include a statement of the specific aim or improvement goal; a list of the key themes, or drivers, that are theorized to require improvement in order to achieve the aim; and lastly a list of the discrete change ideas or initiatives to be tested to determine whether or not they affect discrete drivers, and therefore the overall aim. Because most system outcomes are driven by multiple factors, a KDD allows a QI team to depict a theory that addresses multiple factors. Similarly, Lean and Six Sigma projects use a tool called an A3 that, in addition to organizing the theory of a project, also prompts teams to assess the current state and consider timelines and personnel for planned change (examples are available at https://www.lean.org/common/display).

There are additional QI tools to help assess the current state of a system to better understand how to improve it. One, the **failure modes and effects analysis (FMEA)**, also helps teams develop change ideas (Fig. 4.4). Starting with a map of the processes in the current system, FMEA then asks teams to investigate and brainstorm the many ways discrete processes can go wrong—the *failure modes*. Once failure modes are identified, teams begin to develop discrete interventions or countermeasures to address the failures (see Chapter 5). A similar tool, the **fishbone** or **cause-and-effect** diagram, is organized around key components in a system (e.g., people, material, machines) and helps a team catalog how deficiencies in each component can affect the overall outcome of a system.

Another tool to help teams prioritize action is a **Pareto chart**, which organizes system deficiencies in terms of their prevalence (Fig. 4.5). A Pareto chart typically displays the individual prevalence of discrete problems, determined by baseline analysis of data, as well as the cumulative prevalence, helping teams see which problems should be addressed first to maximize impact on the overall outcome.

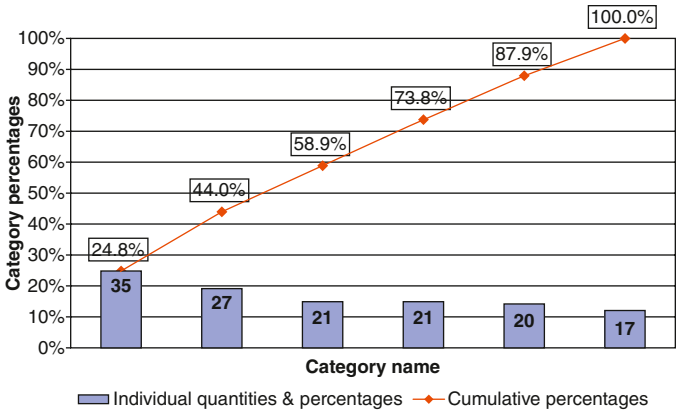

Fig. 4.5 Pareto chart.

Table 4.1 Properties of Robust Quality Measures

ATTRIBUTE	RELEVANCE
Validity	Indicator accurately captures the concept being measured.
Reliability	Measure is reproducible.
Feasibility	Data can be collected using paper or electronic records.
Usability	Measure is useful in clinical practice.

MEASURING QUALITY

Robust quality indictors should have clinical and statistical relevance. *Clinical relevance* ensures that the indicators are meaningful to patient care from the standpoint of patients and clinicians. *Statistical relevance* ensures that the indicators have measurement properties to allow an acceptable level of accuracy and precision. These concepts are captured in the national recommendations that quality measures must meet the criteria of being valid, reliable, feasible, and usable (Table 4.1). **Validity** of quality measures refers to the measure being an estimate of the true concept of interest. **Reliability** refers to the measure being reproducible and providing the same result if retested. It is important that quality measures are **feasible** in practice, with an emphasis on how the data supporting the measures are collected. Quality measures must be **usable**, which means that they should be clinically meaningful. The Agency for Healthcare Research and Quality (AHRQ) and the National Quality Forum have provided specific criteria to be considered when developing quality measures.

Several categories of quality measures can be used to measure the performance of healthcare systems: structure, process, outcome, and balancing. **Structure** refers to the *organizational characteristics* in healthcare delivery. Examples of organizational characteristics are the number of physicians and nurses in an acute care setting and the availability and use of systems such as electronic health records (EHRs). **Process** measures estimate how services are provided; examples are the percentage of families of children with asthma who receive an asthma action plan as part of their office visit and the percentage of hospitalized children who have documentation of pain assessments as part of their care. **Outcome** measures refer to the final health status of the child; examples are risk-adjusted survival in an intensive care unit setting, birthweight-adjusted survival in the neonatal intensive care unit (NICU) setting, and the functional status of children with chronic conditions such as cystic fibrosis. **Balancing measures** are often used to ensure changes in processes or systems do not have unintended consequence. If a healthcare system is actively working to reduce hospital length of stay for common conditions, it would be beneficial to ensure that hospital readmission rates are not increasing.

It is important to distinguish between measures for accountability and measures for improvement. Measures, particularly measures for accountability that may be linked to attribution and payment, must be based on a rigorous process (Fig. 4.6). This can be resource-intensive and time-consuming. In contrast, measures for improvement serve a different purpose—to track incremental improvements linked to specific QI efforts. These may not undergo rigorous testing, and they often have limited applicability beyond the specific QI setting.

Quality data can be quantitative and qualitative. *Quantitative* data includes numerical data, which can be *continuous* (patient satisfaction scores represented as a percentage, with higher numbers indicating better satisfaction) or *categorical* (patient satisfaction scores from a survey using a Likert scale indicating satisfactory, unsatisfactory, good, or superior care). Data can also be *qualitative* in nature, which includes nonnumerical data. Examples of qualitative data can include results from open-ended surveys related to the experience of care in a clinic or hospital setting.

Data measuring quality of care can be obtained from a variety of sources, which include chart reviews, patient surveys, existing administrative data sources (i.e., billing data), disease and specialty databases, and patient registries, which track individual patients over time. Sources of data vary in terms of reliability and accuracy, which will influence *rigor* and therefore appropriate-use cases for the data; many national databases invest significant resources in implementing processes to improve data reliability and accuracy. Data quality can become a significant impediment when using data from secondary sources, which can adversely affect the overall quality evaluation.

Health information technology (HIT) is a critical component in the effort to improve quality. EHRs have resulted in an unprecedented rise in available healthcare data, including traditional, structured data fields such as patient demographic and billing diagnosis codes, as well as unstructured data such as written clinician documentation in notes and imaging studies. The 21st Century Cures Act aims to facilitate the exchange and use of electronic health information "without special effort" on the part of the user. The Cures Act was designed to address concerns about interoperability and usability of electronic health systems, which can be barriers to care, improvement, and research.

The potential applications of big data in quality improvement are far reaching and include advancements in clinical informatics designed to better predict, manage, and treat common illnesses and provide effective, evidence-based, real-time, clinical decision-making support. For example, the Hospital for Sick Children at the University of Toronto is using a real-time data gathering and analysis framework to detect subtle changes on infant heart monitors that may predict potential cases of late-onset neonatal sepsis.

ANALYZING QUALITY DATA

The classic statistical approach from a research paradigm has been applied to quality data for comparing trends over time and differences before and after an intervention. Another approach from an improvement science paradigm uses techniques such as run charts and statistical process control (SPC) charts to track data longitudinally to assess for changes in a system over time. There are several advantages to using run or SPC charts when analyzing quality

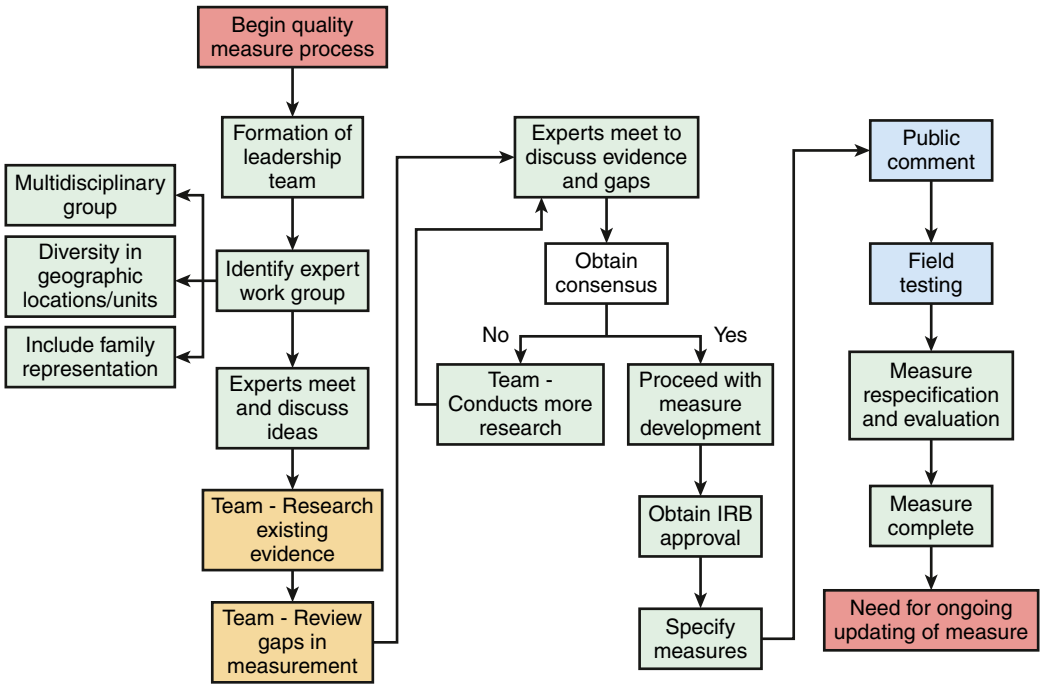

Fig. 4.6 Development of a rigorous quality measure.

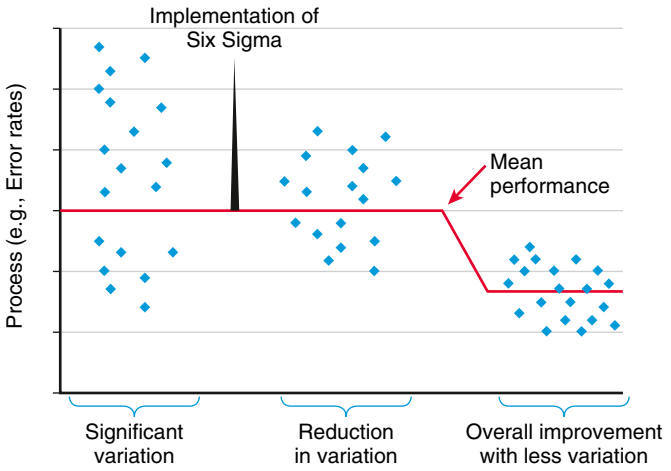

Fig 4.7 Run or SPC chart with common cause and special cause variation.

data—for example, these tools allow evaluation of the effectiveness of various interventions in near real time. Additionally, when using an SPC chart QI teams can also more clearly assess how variation in a process or system is changing over time. Two types of variations are important to distinguish between. **Random variation**, also called *common cause variation,* refers to the variation that is inherent in a process and is expected in any system. In contrast, **special cause variation** refers to nonrandom variation that can affect a process and implies something in the system has been perturbed. When tracking infection rates in a nursery, for example, a sudden increase in the infection rates may be secondary to a planned or unexpected change in a product or supply critical to infection prevention. This would represent a special cause variation; once the supply issue is resolved or mitigated, the system perturbation is resolved, and the infection rates will likely go back to the baseline level. Alternatively, improvement ideas are intended to perturb the system positively such that outcomes improve, ideally without exacerbating the variation in the system (Fig. 4.7). Both run and SPC charts have established rules to assess for special cause variation or a statistically significant change in a process or system over time.

EXPANDING INDIVIDUAL QUALITY IMPROVEMENT INITIATIVES TO SCALE

Despite the success of individual QI projects, the overall progress to achieve large-scale improvements to reach all children across the spectrum of geographic location and SES remains limited. This contributes to the health disparities that persist for children, with significant differences in access and quality of care. A potential factor that limits the full impact of QI is the lack of strategic alignment of improvement efforts with hospitals, health systems, and across states.

This challenge can be viewed from a system standpoint in being able to conduct and expand QI from a micro level (individual projects), to the meso level (regional), to the macro level (national and international). The learning from individual QI projects for addressing specific challenges can be expanded to the regional level by ensuring that there is optimal leadership, opportunity for education, and adoption of improvement science (Fig. 4.8). To further expand the learning to a national and international level, it is important to leverage implementation science to allow a strategic approach to the identification of the key factors that influence success. To leverage fully the synergies in order to impact the quality of care delivered to children, it is important for national and international healthcare organizations to collaborate effectively from a knowledge management and improvement standpoint (Table 4.2).

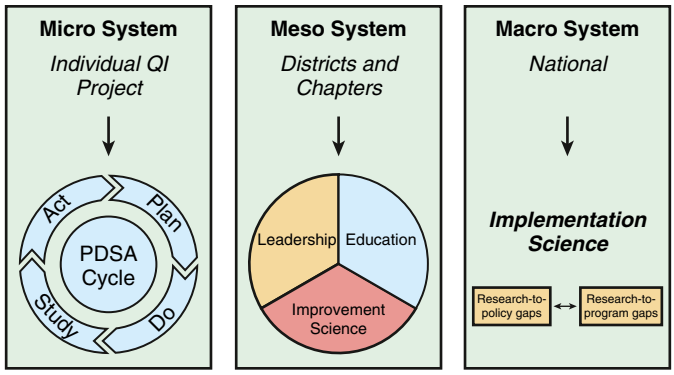

Fig. 4.8 Progressing from small scale to large scale quality improvement.

COMPARING AND REPORTING QUALITY

At the health system level, there is an increasing emphasis on quality reporting in healthcare in the United States. Many states have mandatory policies for the reporting of quality data. This reporting may be tied to reimbursement using the approach of pay-for-performance (P4P), which implies that reimbursements by insurers to hospitals and physicians will be partially based on the quality metrics. An extension of the P4P concept relates to the implementation of the policy of **nonreimbursable hospital-acquired conditions**, formerly called *never events* by the Centers for Medicare and Medicaid Services (CMS). CMS has identified a list of hospital-acquired conditions, which are specific quality events that will result in no payment for subsequent care provided to patients, such as wrong-site surgery, central line–associated bloodstream infections (CLA-BSIs), and pressure ulcers. This approach has not yet been widely implemented for pediatric patients.

There are growing, internet-based, commercial platforms for sharing information about patient and family experiences of care with specific clinical sites and specific providers. Many children's hospitals have also developed their own websites for voluntarily reporting their quality information, including ratings of care experiences. Although greater transparency may provide a competitive advantage to institutions, the underlying policy goal of transparency is to improve the quality of care being delivered and for families to be able to make informed choices in selecting hospitals and providers for their children.

When comparing quality measures across clinical settings, it is important to perform risk adjustments. **Risk adjustment** is the statistical concept that uses measures of underlying severity or risk so that the outcomes can be compared in a meaningful manner. The importance of risk adjustment was highlighted in the pediatric intensive care unit (PICU) setting many years ago. The unadjusted mortality rate for large tertiary care centers was significantly higher than that for smaller hospital settings. However, after **severity of illness** risk adjustment, it was subsequently shown that the risks in tertiary-care, large PICUs were higher because patients had, in general, greater severity of illness. Although this concept is intuitive for most clinicians, the use of severity of illness models allows mathematical estimates of patient severity using physiologic and laboratory data and permits meaningful comparisons of the outcomes across institutions, which may care for patient populations varying in complexity and acuity.

At the individual physician level, quality measures may also be used for purposes of certification as part of the MOC process. In the past, specialty and subspecialty certification in medicine, including pediatrics, was largely based on demonstrating a core fund of knowledge by being successful on an examination. Further, no specific evidence of competency in actual practice needed to be demonstrated beyond successful completion of a training program. However, significant variation in practice patterns among

Table 4.2 National Organizations Involved in Pediatric Quality Improvement (QI)

ORGANIZATION	ROLE	ACTIVITIES
American Academy of Pediatrics (AAP)	Represents more than 60,000 pediatricians and pediatric subspecialists worldwide	Resources for QI to improve health for all children, best practices, advocacy, policy, research and practice, and medical home
American Board of Pediatrics (ABP)	Certifying board for pediatrics and pediatric subspecialties	Certification policies and resources for activities such as Maintenance of Certification (MOC)
American Medical Association (AMA)	Physician member association	Physician Consortium for Performance Improvement (PCPI)—physician-led initiative
Children's Hospital Association (CHA)	Formerly the National Association of Children's Hospitals and Related Institutions and the Child Health Corporation of America	Databases, QI collaboratives, and policy
Institute for Healthcare Improvement (IHI)	QI organization for adult and pediatric care	QI collaboratives, QI educational workshops and materials
National Initiative for Child Health Quality (NICHQ)	QI organization for pediatric care	QI training, improvement networks
The Joint Commission (TJC)	Hospital accreditation organization	Unannounced surveys to evaluate quality of care in hospitals
National Committee for Quality Assurance (NCQA)	QI organization	Healthcare Effectiveness Data and Information Set (HEDIS) and quality measures for improvement
National Quality Forum (NQF)	Multidisciplinary group including healthcare providers, purchasers, consumers, and accrediting bodies	Endorsing national quality measures, convening expert groups, and setting national priorities

physicians who are board certified has demonstrated how medical knowledge is important, but not sufficient, for the delivery of high-quality care. In response, the American Board of Medical Specialties, including its member board, the American Board of Pediatrics, implemented the MOC process in 2010. Within the MOC process, there is a specific requirement (Part IV) for the physician to demonstrate the assessment of their quality of care and implementation of improvement strategies as part of recertification in pediatrics and pediatric subspecialties. Lifelong learning and the translation of learning into practice are the basis for the MOC process and an essential competency for physicians' professionalism. This concept has also filtered in to graduate medical education, as demonstrated by the Accreditation Council for Graduate Medical Education requirement for residency programs to incorporate QI curriculum to ensure that systems-based practice and QI are part of the overall competencies within accredited graduate medical training programs.

IMPLICATIONS OF THE U.S. HEALTHCARE REFORM FOR QUALITY

Regarding quality of healthcare for children, healthcare reform efforts had three key implications. First, expanded insurance coverage optimized access and include expanded coverage for young adults to age 26 years. Second, various initiatives related to quality, safety, patient-centered outcomes research, and innovation were implemented and funded. For example, the AHRQ funded a national effort to establish 7 centers of excellence through the **Pediatric Quality Measurement Program** (PQMP) to improve existing pediatric quality measures and create new measures that can be used by states and in a variety of other settings to evaluate quality of care for children. Third, reform advocated a paradigm shift in the existing model of healthcare delivery from vertical integration toward a model of *horizontal* integration. This has led to the creation and rapid growth of integrated delivery systems and risk-sharing relationships through **accountable care organizations (ACOs)**. Population health outcomes from these changes remain uncertain, although it appears healthcare cost inflation may have slowed somewhat.

Another area of increasing emphasis is **population health**. This is important because it expands the traditional role of physicians to improve quality of care for individual patients to also improve the quality of care for larger populations. Populations can be defined by geographic constraints or disease/patient condition. Efforts to link payment and reimbursement for care delivery by physicians and health systems are being increasingly tied to measurable improvements in population health and demonstration of improved value. To achieve a meaningful improvement in population outcome, physician practices will need to embrace the emerging paradigm of practice transformation, whose many facets include the adoption of a **medical home**, the seamless connectivity across the primary care and subspecialty continuum, and a strong connection between the medical and social determinants of healthcare delivery. To implement successful practice transformation, health systems are increasingly striving to evolve to serve children across the entire range of the care continuum, including preventive and primary care and acute hospital care, and to partner with community organizations for enhancing social supports. In addition, new risk-sharing payment models are being developed, such as value-based purchasing, which represent a financial risk-sharing model across primary and subspecialty care and hospitals.

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Chapter 5

Safety in Healthcare for Children

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Children may be harmed by the healthcare that aims to make them better. Such harms include central line–associated bloodstream infections (CLA-BSIs) and medication errors. In 1991 the Harvard Medical Practice Study reviewed adult medical records from New York State and found that adverse events occurred in an estimated 3.7% of hospitalizations. Most events gave rise to serious disability, and 13.6% led to death. The National Academy of Medicine estimated that as many as 98,000 Americans per year die in the hospital from medical errors.

Although fewer data are available for children, it is evident that children experience substantial healthcare-related harm. Nationally, hospitalized children experience approximately 1,700 CLA-BSIs and 84,000 adverse drug events each year. Although the evidence is less robust, and not without controversy, substantial progress has been reported, particularly in **healthcare-associated conditions (HACs)**. Less strong epidemiologic estimates are available for adverse events in the ambulatory environment, but these events are likely more common than reported.

The **Solutions for Patient Safety (SPS)** collaborative includes >145 children's hospitals across the United States and Canada (http://www.solutionsforpatientsafety.org) and uses a learning network model to pursue the aim of eliminating serious harm across all children's hospitals. In addition, healthcare has recognized the high rates of healthcare worker injury and the critical role that the safety of healthcare providers plays in outcomes, burnout, and safe patient care.

ERROR VS HARM

Clinical leaders, improvers, and researchers often employ measures of error and harm to understand and improve safety, but the differences between these two measures can lead to confusion. **Errors** occur when a member of the healthcare team does the wrong thing *(error of commission)* or fails to do the right thing *(error of omission)*; errors of omission (e.g., not arriving at the right diagnosis) are considerably more difficult to measure. **Harm**, as defined by the Institute for Healthcare Improvement, is "unintended physical injury resulting from or contributed to by medical care (including the absence of indicated medical treatment), that requires additional monitoring, treatment, or hospitalization, or that results in death." Most errors in healthcare do not lead to harm; harm may be both preventable and nonpreventable (Fig. 5.1). A physician may erroneously fail to add a decimal point in a medication order for an aminoglycoside antibiotic, ordering a dose of 25 mg/kg rather than the intended dose of 2.5 mg/kg. If this error is caught by the computerized order entry system or the pharmacist, this would be an error with no resultant harm. If this error was not caught and reached the patient, who suffered acute kidney injury, this would be *preventable* harm since evidence shows that pharmacist review can reduce the risk of these errors 10-fold. Alternatively, if a patient received a first lifetime dose of amoxicillin and had anaphylaxis requiring hospital admission, this harm would be considered *nonpreventable* since no valid predictive tests are available for antibiotic allergy. Furthermore, the concept of **latent risk**, independent of any actual error, is inherent in any system where patients can be harmed. Among errors that do not lead to harm, **near misses** that do not reach patients—or high-risk situations that do not lead to harm because of good fortune or mitigation—are important learning opportunities about safety threats.

Several classification systems exist to rate harm severity, including the National Coordinating Council for Medication Error Reporting and Prevention (NCC-MERP) Index for medication-related harm and the severity scales for all-cause harm. **Serious safety events (SSEs)** are deviations from expected practice followed by death or severe harm. The SPS collaborative has SSE elimination as its primary goal. **Sentinel events** or **never events**, such as a wrong-site surgery, are also targets of external reporting and for elimination through quality improvement (QI) initiatives (see Chapter 4). Increasingly, health systems are using a *composite serious harm index,* which combines a variety of preventable HACs (e.g., CLA-BSIs) to examine system safety performance over time across various patient populations and sites of care.

SAFETY FRAMEWORKS

Safety frameworks are conceptual models and tools to help clinicians, improvers, and researchers understand the myriad contributors to safe healthcare and safety events. Healthcare is delivered in a complex system with many care providers and technologies, such as electronic health records and continuous physiologic monitors. The Donabedian framework, which links structure, process, and outcome, can be a very useful tool. The **Systems Engineering Initiative for Patient Safety (SEIPS)** model, developed by human factors engineers, cognitive psychologists, and physicians, provides more detailed tools to understand the work system and the complex interactions between people (including the patient and family) and task work and technology and the environment. The SEIPS 3.0 model uses the concept of the "patient journey" to describe a patient's interactions with multiple complex and separate care settings over time. Other available safety frameworks include those from the Institute for Healthcare Improvement. The "Swiss cheese" model illustrates how multiple components of an organization's defenses prevent failures from leading to harm, but harm may occur when multiple defenses fail at the same time (Fig. 5.2).

Traditionally, safety science and improvement have focused on identifying *what went wrong* (near misses, errors, and harm) and then tried to understand and improve the system of care that led to these events (Safety-I framework). There is increasing focus on *what goes right*. This framework, called *Safety-II,* brings focus on the much greater number of things that go right and how people act every day to create safety in complex and unpredictable systems. Safety-II seeks to learn from people, the greatest source of system resilience, particularly in the midst of high levels of risk and stress, as often seen in healthcare.

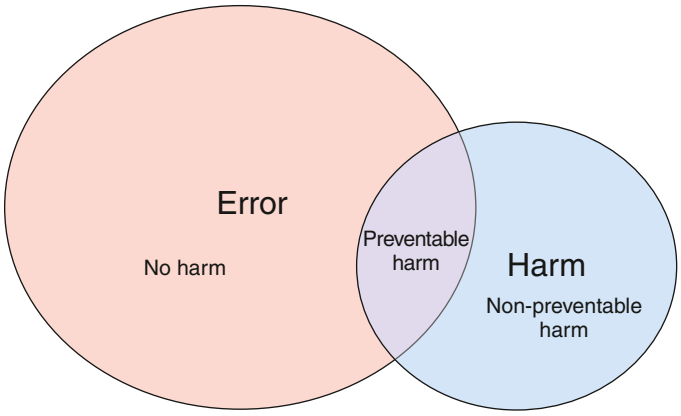


Fig. 5.1 Overlap between error and harm.

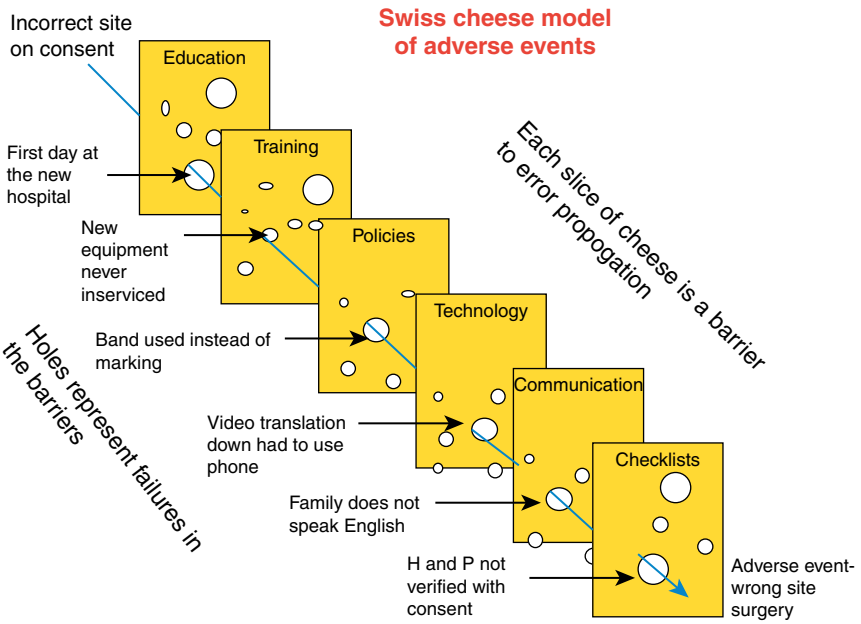


Fig. 5.2 The Swiss cheese model of adverse events. (*From Stein JE, Heiss K. The Swiss cheese model of adverse event occurrence—Closing the holes.* Semin Pediatr Surg. *2015;24[6]:278–282.)*

IDENTIFYING AND ANALYZING HARM, ERRORS, AND LATENT THREATS

Health systems use a toolbox of processes to discover, understand, and mitigate unsafe conditions.

Incident Reporting Systems

Many health systems and hospitals offer employees access to a system to report errors, harms, or near misses. Most frequently, these are anonymous so that healthcare workers feel safe to submit an event in which they may have been involved or when the harm involved someone in a position of authority. Ideally, these systems facilitate smooth and efficient entry of enough information for further review but avoid excessive burden of time or cognitive load on the reporter. **Incident reporting** systems likely work best in the presence of a strong safety culture and when employees have some confidence that the event will be reviewed and actions taken. The chief limitation of incident reporting systems is that incident reports dramatically *underreport* safety events. Thus other mechanisms must also be in place to learn about safety. **Trigger tool** systems use *triggers,* such as the need for an antidote to an opioid overdose or the transfer of a patient to higher-level care, to facilitate targeted medical record review by trained nurses and physicians to elucidate any errors or system risks.

Simulation

Simulation is an excellent tool to better understand system and latent threats. *High-fidelity simulation,* which involves the use of a manikin that can reproduce or mimic human anatomy and physiology, can allow clinicians to practice technical skills such as intubation in a safe environment. Perhaps more importantly, simulation can help clinical teams improve nontechnical skills such as using closed-loop communication and sharing a mental model (e.g., a team leader states, "I believe this patient has septic shock. We are rapidly infusing fluids and giving antibiotics. Blood pressure is normal for age. What other thoughts does the team have?"). It is often easier and more feasible to give feedback in a simulated scenario versus a real event.

Low-fidelity simulation does not require costly simulated patients and may have advantages in identifying latent threats in the hospital or clinic. For example, a simulated scenario on a medical-surgical unit might identify that nurses do not know where to find a mask for continuous positive airway pressure (CPAP) to support an infant with respiratory failure. Identifying—and then mitigating—this latent threat in a simulated environment is preferable to doing so in an acutely deteriorating child.

Event Analysis

Several types of event analysis, including root cause analysis, apparent cause analysis, and common cause analysis, can help teams understand—and later mitigate—the causes of adverse events. Each model has its own strengths and weaknesses. **Root cause analysis (RCA)** is a robust and time-intensive process to ascertain the most fundamental, or *root*, causes of a safety event. The Joint Commission requires the use of RCA on sentinel events. Most health systems reserve this methodology primarily for sentinel events, because RCAs can take months to complete and require convening a multidisciplinary team of experts. The safety event and its antecedents are reviewed in detail with a focus not on human behavior, but instead on systems, hazards, and latent errors. The RCA team works to go beyond the event (e.g., enteral formula feeds connected to and administered through a central line) to the proximal causes (e.g., "feeding tube and intravenous tubing are visually identical and are easily attached") and root cause (e.g., "organization lacks a system to assess human factors risks as new equipment is procured and put into practice"). When root causes are identified and tied to robust improvement action plans, safety can be substantially improved (e.g., "we will design feeding tubing and intravenous tubing to be distinct and incompatible"). In addition to the time-intensive nature of RCAs, *hindsight bias* is a risk and needs to be managed carefully by the team. Additional challenges with RCAs include the potential to *overfit solutions*—designing protocols or procedures that may have reduced the risk of the specific safety event reviewed but also introduce new problems and increase the probability of other safety threats—as well as difficulties in spreading solutions to different care areas that often have different needs, processes, and goals.

Apparent cause analysis, common cause analysis, and failure modes and effects analysis are complementary learning methods. **Apparent cause analysis** is performed by a smaller multidisciplinary team to look primarily for proximal causes, making it feasible for events that occur often (e.g., the wrong medication is sent from the pharmacy). Importantly, in each analysis the team works to determine how likely it is that such an event will occur in the

future and how widespread the proximate causes are in the microsystem. **Common cause analysis** seeks to aggregate learning across multiple events. A similar common cause, such as poor handoff procedures, may lead to different safety events (e.g., a missed laboratory check and a delayed diagnosis); common cause analysis aids leaders in determining this. **Failure mode and effects analysis (FMEA)** is a powerful tool that clinicians use to describe a process and identify *failure modes,* or ways in which each step might fail. A more robust and quantitative form of FMEA rates potential failure modes in three categories: probability of event occurring, its severity, and its ability to be detected. The product of these, called the *risk priority number,* can help a team identify which failure modes may lead to the greatest harm and thus which to target first.

SAFETY CULTURE

A broad and supportive safety culture likely drives both patient and employee safety outcomes. An organization with a mature safety culture fosters a culture of learning and treats errors as opportunities to improve the system, rather than as the personal failures of individual clinicians. *Just culture* differentiates the mistakes and wrong decisions that a clinician makes commensurate with their training and experience from willful violations and gross or repeated patterns of negligence. A safety culture prioritizes clear and consistent communication and teamwork and aims to ease authority gradients (described later). Several tools are available to measure safety culture, including the Safety Attitudes Questionnaire and the Agency for Healthcare Research and Quality (AHRQ) surveys on Patient Safety Culture. A strong safety culture supports transfer of responsibility within disciplines at handoffs and across disciplines (e.g., when a nurse is calling a physician with a new concern). Structured communication tools such as the **Situation-Background-Assessment-Recommendation** (SBAR) approach are valued in a safety culture, as are safety behaviors such as "repeat back or write back," when a critical laboratory result is shared and repeated back by the receiving clinician.

Authority gradients are quite real in healthcare. In a culture of safety, both junior and senior clinicians work together across disciplines to speak up when concerns are identified, to ask questions, and not to proceed if there is uncertainty about safe patient care. Health system leaders have a critical role in supporting this culture, orienting new employees to its importance, and stepping in if authority gradients or disruptive behaviors contribute to safety events or unsafe conditions. To address the adverse impact of the healthcare hierarchy on providing safe care, recent efforts have focused on *psychologic safety.* Psychologic safety is defined as the ability to raise concerns and ask questions without the fear of negative consequences for self-image, status, or career. This concept is critical for multiple aspects of safety culture, including establishing a shared mental model, event reviews and debriefs, addressing professionalism concerns, and effectively partnering with patients and families to pursue safety goals.

RELIABILITY SCIENCE, HUMAN FACTORS ENGINEERING, AND HIGH-RELIABILITY ORGANIZATIONS

Reliability in healthcare is defined as the measurable capability of a process, procedure, or health service to perform its intended function in the required time under commonly occurring conditions. Most processes in healthcare organizations currently perform at **Level 1** reliability, meaning a success rate of only 80–90%. To achieve **Level 2** performance (≤5 failures/100 opportunities), processes must be *intentionally designed* with tools and concepts based on the principles of **human factors engineering** and **reliability science**. These processes include creating intentional redundancy, such as independent verification on high-risk medication dosing, and making the default action the desired action based on evidence, such as a default to an influenza vaccination for high-risk patients with asthma. Performance at **Level 3** (≤5 failures/1,000 opportunities) requires a well-designed system with low variation and cooperative relationships and a state of "mindfulness," with attention to processes, structure, and their relationship to outcomes.

Healthcare can learn important safety lessons from disciplines such as human factors engineering and cognitive psychology. Industries that better leverage learnings from these disciplines—and robustly identify and mitigate threats and use simulation—include commercial aviation and nuclear power, termed *high-reliability organizations*. These organizations achieve exemplary safety records under dynamic and high-risk conditions through consistent application of five tenets: (1) a preoccupation with failure—surprises and errors are thought of as learning opportunities, and learnings spread quickly through the organization, (2) reluctance to simplify interpretations—serious safety events receive an RCA, (3) sensitivity to operations—proactive assessments and huddles target risks to patients and the organization, (4) a commitment to resilience—errors do not disable, and high-risk, uncommon scenarios are negotiated, and (5) deference to expertise—leaders defer to frontline experts when their knowledge is required.

SERIOUS HARM EVENTS AND HEALTHCARE-ASSOCIATED CONDITIONS

Substantial improvement in patient safety has occurred through improvement teams targeting *serious harm* events. The **serious harm event rate** is a composite metric that groups preventable HACs into one number (usually a rate per at-risk patient-days), so that an organization or collaborative can track progress on a variety of conditions with one metric and chart. Table 5.1 lists frequently targeted HACs. Commonalities among successful improvement teams targeting these HACs include multidisciplinary team membership, clear outcome definitions and measurement, learning systems around each HAC, and attention to both process and outcome measures. Many of the successes with CLA-BSIs were associated with targeted improvements to reliably adhere to a line insertion bundle and a line maintenance bundle. Figure 5.3 illustrates coincident improvements in process measures and outcomes measure in a hypothetical CLA-BSI project. In this case, after improvement interventions targeted two process measures known to be important in CLA-BSI risk—the line insertion and the line maintenance bundles—the QI team saw improvement in both measures and coincident reduction in CLA-BSIs.

A safety culture and experienced improvement teams are consistent drivers of success. A **learning network model**, as used in SPS, is effective in bringing project teams together from different hospitals to discuss lessons learned and common barriers faced and negotiated.

SAFETY OPPORTUNITIES AND GAPS

In addition to HACs, several other safety events are the targets of active study and improvement. Unrecognized clinical deterioration in hospitalized children, diagnostic error, poor handoffs across multiple stakeholders, and alarm/alert fatigue lead to substantial and preventable harm. There are also important considerations for improving safety in unique sites of care, including the surgical and ambulatory environments. Additionally, it is increasingly clear that patient safety improvements might be limited if the field does not also target improved occupational safety of those who provide care.

Clinical Deterioration

The deterioration of hospitalized patients is rarely a sudden and unpredictable event; rather, it is often preceded by abnormal vital signs and concerns from patients, families, and clinicians. **Rapid response systems** are designed to detect deterioration and then deploy teams with critical care expertise to provide treatment or escalate care to an intensive care unit (ICU). Although variation remains in how these teams

Table 5.1 Common Healthcare-Associated Conditions (HACs) Targeted in Quality Improvement Efforts with Interventions

HAC	DEFINITION	COST PER EVENT	POTENTIALLY EFFECTIVE INTERVENTIONS
Central line–associated bloodstream infections	Laboratory-confirmed bloodstream infection with central line in place at time of or 48 hr before onset of event (details at https://www.cdc.gov/nhsn)	$55,646	Line insurance bundle (e.g., handwashing, chlorhexidine scrub), maintenance bundle (catheter care, change dressing, discuss daily if catheter is needed)
Catheter-associated urinary tract infections	Urinary tract infection where an indwelling urinary catheter was in place >2 days on day of event (details at https://www.cdc.gov/nhsn)	$7,200	Protocols for reviewing and removing catheters daily, clear indications for inserting catheters, physician champions, audit and feedback of data
Adverse drug events	Harm associated with any dose of a drug (details at http://www.nccmerp.org/types-medication-errors)	$3,659	Pharmacist review of medication order, computerized physician order entry, co-ordering of laxatives in patients on opiates
Peripheral IV infiltrates	Moderate or serious harm (e.g., diminished pulses, >30% swelling) associated with a peripheral IV infiltrate (details at http://www.solutionsforpatientsafety.org)	—	Hourly reviews of IV status, limitations on use of desiccants through peripheral IVs, remove IVs when no longer needed
Pressure injuries	Localized damage to skin and/or underlying soft tissue usually over a bony prominence or related to a device (details at http://www.solutionsforpatientsafety.org)	—	Screening of high-risk patients (e.g., Braden Q Scale), regular turning of low-mobility patients, regular inspection and skin care; specialized device padding
Surgical site infections	Infection of incision or deep tissue space after operative procedure (details at https://www.cdc.gov/nhsn)	—	Surgical checklist, antimicrobial prophylaxis within 60 min before incision, preoperative baths, postoperative antibiotic redosing
Venous thromboembolism	Blood clot in deep vein, stratified as central line–associated vs not (details at https://www.cdc.gov/nhsn)	$27,686	Screening for high-risk patients, removal of central line catheters when no longer needed, targeted prophylaxis

are activated and staffed, all U.S. children's hospitals have some version of a rapid response system. The initiation of rapid response teams is associated with a significant reduction in codes outside the ICU and in-hospital mortality.

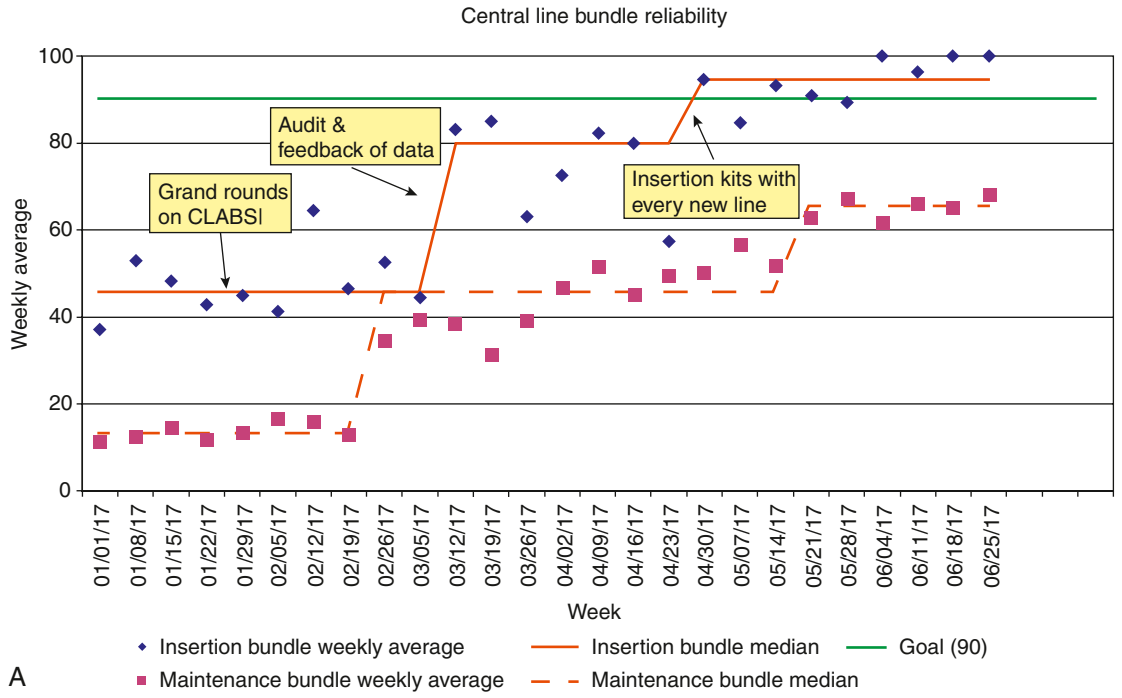
Pediatric early warning scores (PEWS) are used in many large children's hospitals to identify deteriorating patients by assigning scores based on the degree of abnormalities in different body systems. Different versions of PEWS are often employed, but all include scores driven by age-based vital signs and nursing assessments in areas such as mental status and perfusion. Importantly, PEWS take these diverse exam elements and combine them into a single score, which when coupled with clear, expected actions (e.g., evaluation by physician at score of 5, evaluation by rapid response team at score of 7) may better detect deterioration and improve safety outcomes.

PEWS are one method of improving a clinician's *situation awareness*—the sense of what is going on around the clinician, the notion of what is important, and the anticipation of future consequences. Maintaining situation awareness can be challenging in dynamic, high-risk environments such as healthcare. Work at several children's hospitals to improve situation awareness has been associated with sustained and significant reductions in unrecognized clinical deterioration. This improvement work first designed systematic and proactive identification of *watcher* patients, or those a nurse, physician, or patient family felt were close to the edge of deterioration. These high-risk patients are discussed at multidisciplinary bedside "huddles," and specific treatment plans and predictions are outlined. Concerns are more fully addressed through the rapid response team and at hospital-wide safety huddles and safety rounds. To gain a better sense of organization safety and performance threats, many hospitals in the SPS collaborative employ a daily safety or operations brief, where leaders from a variety of service lines (e.g., inpatient, pharmacy, perioperative care) can discuss unexpected events and rapidly develop solutions and follow-up plans to mitigate emerging threats that cross disciplines. Event debriefs and reviews are particularly relevant for instances of clinical deterioration. They serve multiple purposes, including the emotional processing of an event, a discussion of the process of care and team performance, and the development of action plans to improve care in the future. The Pediatric Resuscitation Quality Collaborative (pediRES-Q: https://www.pedires-q.org/) classifies debriefs into two types: (1) "hot" debriefs, which occur minutes to hours after the event and allow for emotional processing and educational discussion, and (2) "cold" debriefs, which occur days to weeks after the event and allow for a comprehensive, multidisciplinary review of all data and feedback. Current research and improvement efforts in this area are focused on developing successful frameworks to guide discussions and action plan development, such as formal processes for classifying and reviewing cardiac arrest events in the pediatric ICU.

Cardiopulmonary arrest rates outside of the ICU are useful metrics to evaluate the performance of rapid response systems in adult patients. Given that these events are quite rare in pediatrics, and increasingly so since the implementation of rapid response systems, the identification of valid, more frequent proximal metrics is a focus of research efforts. Table 5.2 describes proximal metrics to arrest and the types of code events used to identify risk factors for unrecognized deterioration and evaluate rapid response system effectiveness in pediatrics.

Diagnostic Error

Diagnostic error is recognized as an increasingly common and impactful event, with 10–15% of diagnoses estimated to be incorrect. There are two systems of clinical decision-making. **System 1** is fast, instinctual, and largely unconscious. **System 2** is slow, effortful, cognitive, and calculating. System 1 and its *heuristics* or *biases* allow for quick—almost automatic—decision-making, often by associating new information with existing patterns or beliefs (e.g., that red object on the right side of the road is a stop sign; I should stop). However, system 1 thinking can be dangerous in diagnosis, particularly when new data are unconsciously made to fit the preconceived pattern and



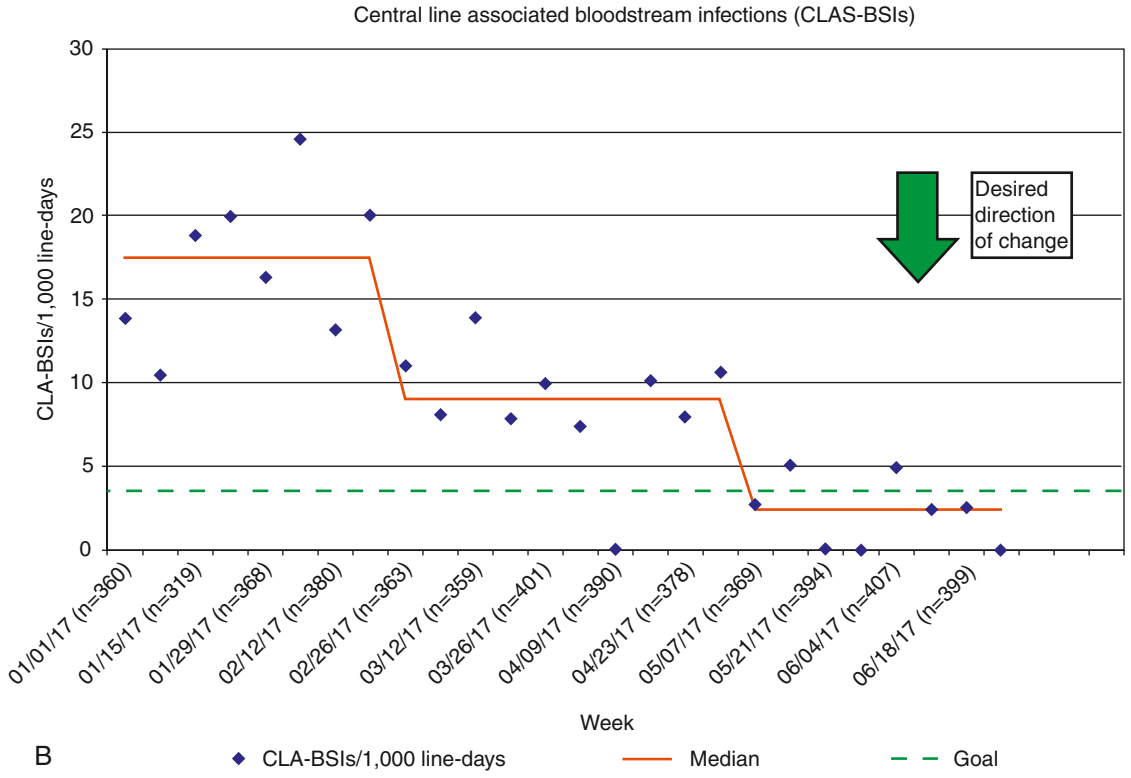


Fig. 5.3 Quality improvement interventions targeted process improvement in the **A,** line insertion bundle, where performance improved from 46% to 95%, and **B,** line maintenance bundle, where performance improved from 13% to 66%. Coincident with the improved bundle performance, the rate of CLA-BSIs fell from 17.6 to 2.5 per 1,000 line-days.

are not seen as disconfirming. Research in this area aims to better understand how well-described cognitive biases (e.g., premature closure, availability bias) play out in clinical care and what system-based strategies can mitigate their effects (Tables 5.3 to 5.5). There are ongoing efforts to move clinicians from system 1 to system 2 thinking, such as being explicit on uncertainty (e.g., patients admitted from the emergency department [ED] as "uncertain diagnosis") or using decision aids to prompt revisiting provisional diagnoses such as the diagnostic time-out or team-based (collective intelligence) thinking (Tables 5.6 and 5.7). Safety culture is critical to both the open acknowledgment of diagnostic uncertainty and the willingness to discuss and learn from diagnostic error when it occurs.

The 2015 National Academy of Medicine (NAM) report entitled *Improving Diagnosis in Health Care* emphasized the centrality of

Table 5.2 Metrics to Identify Risk Factors for Unrecognized Deterioration Outside of the ICU and Evaluate Rapid Response System Performance

METRIC	REFERENCE	DEFINITION	STRENGTHS	LIMITATIONS
Unplanned ICU transfer	Baker 2009 Reese 2015	All patients unexpectedly admitted to the ICU from a lower level of care in the hospital Transfer to the ICU from the inpatient ward that was not expected or previously coordinated (such as a planned ICU admission postoperatively)	More common than code events and other proximal metrics to arrest High sensitivity for unrecognized deterioration	Low specificity for unrecognized deterioration Often requires time-intensive manual review of ICU transfers Site-specific parameters, including definition adjustments, and the acuity of patients cared for outside of the ICU
Critical deterioration event	Bonafide 2012	Noninvasive ventilation, intubation, or vasopressor initiation within 12 hr after ICU transfer	More common than emergency transfers and code events High sensitivity for unrecognized deterioration Increased specificity as compared with unplanned ICU transfers Objective criteria facilitating use in multicenter studies and collaboratives	Less specific than emergency transfers; may include patients with promptly recognized deterioration Often requires time-intensive manual review of ICU transfers
Emergency transfer	Brady 2013	Intubation, inotropic support, or 3 or more fluid boluses in the first hour after arrival or before ICU transfer	More common than code events High specificity for unrecognized deterioration Objective criteria facilitating use in multicenter studies and collaboratives Feasible to track in near-real time	Less common than critical deterioration events and unplanned ICU transfers
Significant clinical deterioration event	Parshuram 2018	Death, cardiopulmonary resuscitation, tracheal intubation, vasoactive medications, or ≥60 mL/kg fluid boluses in the 12 hr before transfer, or death, cardiopulmonary resuscitation, tracheal intubation, or ECMO initiation within 1 hr after ICU transfer	More common than code events Objective criteria facilitating use in multicenter studies and collaboratives	Complex definition not inclusive of all interventions and outcomes associated with acute deterioration events Often requires time-intensive manual review of ICU transfers
Code event: Cardiopulmonary arrests (CPAs)	Children's Hospital Association	Pulselessness or pulse with inadequate perfusion necessitating chest compressions and/or electric shock	High specificity for unrecognized deterioration Objective criteria facilitating use in multicenter studies and collaboratives Feasible to track in near-real time	Less common than proximal metrics to arrest Low sensitivity for inadequately recognized, subacute cases of deterioration
Code event: Acute respiratory compromise (ARC)	Children's Hospital Association	Respiratory insufficiency with bag-valve mask or invasive airway interventions, followed by a transfer to a higher level of care for sustained airway support	High specificity for unrecognized deterioration Objective criteria facilitating use in multicenter studies and collaboratives Feasible to track in near-real time	Less common than proximal metrics to arrest Low sensitivity for inadequately recognized, subacute cases of deterioration Not inclusive of all nonrespiratory etiologies of deterioration

communication to patients and families in the diagnostic process while introducing a diagnostic process model with several important outcomes (Fig. 5.4). The diagnostic process occurs with iterative cycles of information gathering, its integration and interpretation, and the formulation of a working diagnosis. The NAM report brought particular emphasis to the diagnostic team, which includes doctors and nurses in different practice contexts (e.g., the ED and primary care), as well as pharmacists, respiratory therapists, patients, and families. Strategies that aim to leverage the diagnostic team, as opposed to simply the cognition of busy individuals, may be particularly well poised to improved patient-level and system-diagnostic outcomes.

Handoffs/I-PASS

There is a growing evidence base on the consequences of poor handoffs and on complex interventions to improve handoffs and resultant safety outcomes. The best-studied handoff is resident-to-resident shift handoff in teaching hospitals. Use of the **I-PASS** mnemonic—*i*llness severity, *p*atient summary, *a*ction list, *s*ituation awareness and contingency planning, and *s*ynthesis by receiver—and the surrounding educational quality improvement curriculum was associated with a significant 23% reduction in medical errors and 30% reduction in adverse events in a nine-hospital study. Related work has described improved communication by targeting ICU-to-floor, operating room–to–ICU, and inpatient medical team–to–primary care handoffs.

Alarm/Alert Fatigue

Alarm fatigue, when a healthcare provider is subject to so many interruptions that a potentially relevant alarm is not heard, is also an area of active research and improvement. In the hospital, many physiologic monitor alarms occur each day (up to 400 per patient

Table 5.3 Cognitive Biases Related to Heuristic Failure

BIASES	DEFINITION
Anchoring	Locking into a diagnosis based on initial presenting features, failing to adjust diagnostic impressions when new information becomes available
Confirmation bias	Looking for and accepting only evidence that confirms a diagnostic impression, rejecting or not seeking contradictory evidence
Diagnostic momentum	Perpetuating a diagnostic label over time, usually by multiple providers both within and across healthcare systems, despite the label being incomplete or inaccurate
Expertise bias/yin-yang out	Believing that a patient who has already undergone an extensive evaluation will have nothing more to gain from further investigations, despite the possibility that the disease process or diagnostic techniques may have evolved so as to allow for appropriate diagnosis
Overconfidence bias	Believing one knows more than one does, acting on incomplete information or hunches, and prioritizing opinion or authority, as opposed to evidence
Premature closure	Accepting the first plausible diagnosis before obtaining confirmatory evidence or considering all available evidence: "When the diagnosis is made, thinking stops"
Unpacking principle	Failing to explore primary evidence or data in its entirety and subsequently failing to uncover important facts or findings, such as accepting a biopsy report or imaging study report without reviewing the actual specimen or image; especially important in undiagnosed and rare diseases

From Bordini BJ, Stephany A, Kliegman R. Overcoming diagnostic errors in medical practice. *J Pediatr.* 2017;185:19–25, Table I.

Table 5.4 Cognitive Biases Related to Errors of Attribution

BIASES	DEFINITION
Affective bias	Allowing emotions to interfere with a diagnosis, either positively or negatively; dislikes of patient types ("frequent flyers").
Appeal to authority	Deferring to authoritative recommendations from senior, supervising, or "expert" clinicians, independent of the evidentiary support for such recommendations.
Ascertainment bias	Maintaining preconceived expectations based on patient or disease stereotypes.
Attribution error	Placing undue importance on the perceived internal characteristics or motivations of others, whether they are the patient, the patient's family, or other members of the evaluation team.
Countertransference	Being influenced by positive or negative subjective feelings toward a specific patient.
Outcome bias	Minimizing or overemphasizing the significance of a finding or result, often based on subjective feelings about a patient, a desired outcome, or personal confidence in one's own clinical skills. The use of "slightly" to describe abnormal results.
Psych-out bias	Maintaining biases about people with presumed mental illness.

From Bordini BJ, Stephany A, Kliegman R. Overcoming diagnostic errors in medical practice. *J Pediatr.* 2017;185:19–25, Table II.

Table 5.5 Cognitive Biases Related to Errors of Context

BIASES	DEFINITION
Availability bias	Basing decisions on the most recent patient with similar symptoms, preferentially recalling recent and more common diseases.
Base-rate neglect	Prioritizing specific information (e.g., a laboratory value) pertaining to a case while ignoring general base rate information about the prevalence of disease in populations (pretest probability).
Framing effect	Being influenced by how or by whom a problem is described or by the context in which the evaluation takes place.
Frequency bias	Believing that common things happen commonly and usually are benign in general practice.
Hindsight bias	Reinforcing diagnostic errors once a diagnosis is discovered despite these errors. May lead to a clinician overestimating the efficacy of his or her clinical reasoning and may reinforce ineffective techniques.
Posterior probability error	Considering the likelihood of a particular diagnosis in light of a patient's chronic illness. New headaches in a patient with a history of migraines may in fact be a tumor.
Representative bias	Basing decisions on an expected typical presentation. Not effective for atypical presentations. Overemphasis on disease-diagnostic criteria or "classic" presentations. "Looks like a duck, quacks like a duck."
Sutton's slip	Ignoring alternative explanations for "obvious" diagnoses (Sutton's law is that one should first consider the obvious).
Thinking in silo	Restricting diagnostic considerations to a particular specialty or organ system. Each discipline has a set of diseases within its comfort zone, which reduces diagnostic flexibility or team-based communication.
Zebra retreat	Lacking conviction to pursue rare disorders even when suggested by evidence.

From Bordini BJ, Stephany A, Kliegman R. Overcoming diagnostic errors in medical practice. *J Pediatr.* 2017;185:19–25, Table III.

in some environments), and nurses exposed to a high volume of alarms respond more slowly to them. Interventions currently being studied include removing monitors from patients unlikely to benefit from them, designing smart alarms that alert only when certain scenarios occur (e.g., bradycardia in the context of hypoxia), and using advanced communication technology to safely escalate true alarms while ignoring nonactionable alarms. **Alert fatigue** is related to alarm fatigue but refers to clinicians not processing an alert, such as a medication interaction from the electronic health record, when receiving a large burden of alerts often regarded as nonactionable.

Table 5.6 Diagnostic Time-Out

- Identify the clinical issues, dilemmas, or concerns needing a time-out.
- Remove all previous diagnoses and reexamine all laboratory studies, imaging, and other information, including the history and physical exam.
- Did we consider the risks of heuristic (intuitive) thinking?
- Do we have biases?
- What are the diseases we must not miss?

From Bordini BJ, Basel D. Disease mimics: An approach to undiagnosed diseases. In: Kliegman RM, Toth H, Bordini BJ, Basel D. (eds). *Nelson Pediatric Symptom-Based Diagnosis*. 2nd ed. Philadelphia: Elsevier; 2023: Table 1.6.

Surgical Safety

Initially, in response to the problem of wrong-patient or wrong-site surgeries, perioperative leaders developed a set of safety strategies often termed the *tenets of surgical safety,* which are endorsed by the World Health Organization (https://www.who.int/patientsafety/safesurgery/en/). The tenets are implemented as several discrete checklists at key points, or "time-outs," in the workflow around a procedure or surgery. Several studies have demonstrated reduced harm to patients, and surgical checklists are adopted widely throughout surgical and procedural environments. Typically, checklists are used at three key times during a procedure: before induction of anesthesia, before skin incision or insertion of a device into any body cavity or orifice, and before a patient leaves the procedural area or operating room. Key aspects of the impact of this approach include multidisciplinary active participation, visual display of the checklist or other key tools as references, and attention to hierarchies and team-based communication. An evolving area of surgical and procedural safety is the use of simulation and video-based procedure review to improve surgical technique and perioperative team function and to identify latent threats.

Ambulatory Safety

Adverse drug events and medication dosing errors are the best-studied safety events in the outpatient environment. A study of children receiving chemotherapy used direct observation by a trained nurse at home and found approximately 70 errors per 100 patients, many of which were serious or significant. Families often make dosing errors

Table 5.7 Solutions to Avoid Diagnostic Errors

1. Enhancing foundational knowledge in medical education
   - Teach symptoms and their differential pathophysiology, not just diseases.
   - Emphasize red flags and must-not-miss diagnoses.
2. Minimizing errors related to heuristic failure
   - Build understanding of system 1 and system 2 thought processes and the risks of heuristic failure.
   - Actively model and encourage counterfactual reasoning and hypothesis generation to enhance system 2 skills.
3. Mitigating errors of attribution
   - Increase awareness of biases toward specific patients by promoting self-reflection.
   - Use a team-based approach and diagnostic strategies that actively dispel biases.
4. Avoiding errors of context
   - Solicit input across a variety of specialties when appropriate.
   - Consciously acknowledge the risk of thinking in silo and actively seek explanations outside of one's specialty.
5. Optimizing data gathering, analysis, and hypothesis generation
   - Develop differential diagnoses based on pathophysiology; consider alternatives and competing options.
   - Realize that diagnostic criteria for certain diseases do not account for atypical disease manifestations.
   - Rely on objective individual data, not just disease prevalence rates, when considering the pretest likelihood of a particular diagnosis.
   - Avoid diagnostic momentum and question-accumulated diagnostic labels, regardless of who applied the label.
6. Improving hypothesis testing
   - Know the limitations of laboratory tests (i.e., false positives and negatives).
   - Do not be so quick to "rule out" a diagnosis: consider the posttest likelihood of a disease in terms of a probabilistic analysis that applies specifically to the patient.
   - Acknowledge that the initial "working" diagnosis may not always be the final diagnosis.
   - Rely on evidence-based data and avoid authority- or overconfidence-based errors.
   - Recognize that a diagnosis is an iterative and interactive process that should not be bounded by premature closure or anchoring. Be open to both confirmatory and nonconfirmatory data.
   - Both know and accept what you do not know.
7. Critical solutions for complex and undiagnosed and rare-disease patients
   - Maintain healthy skepticism, especially with patients who come prediagnosed.
   - Analyze historical diagnostic data methodically and thoroughly and unpack all data completely. Examine actual studies, such as tissue specimens and imaging investigations, and do not rely on written reports.
   - Question the working diagnosis when findings or the clinical course does not fit.
   - Realize that patients can have more than one disease process.
   - Incorporate all data and avoid minimizing the significance of abnormal results. Do not ignore contradictory clinical, laboratory, or imaging data.
   - Never say "never" or "it cannot be."
   - Use a systematic team-based approach to enhance debiasing, broaden the collective knowledge base, and minimize context-related errors.
   - Be aware that patients with undiagnosed and rare diseases may have an atypical or rare manifestation of a recognizable common disease or may have a rare disease.
   - Use extensive literature review and search strategies based on the patient's phenotype and individual findings and hypotheses.

From Bordini BJ, Stephany A, Kliegman R. Overcoming diagnostic errors in medical practice. *J Pediatr*. 2017;185:19–25, Table V.

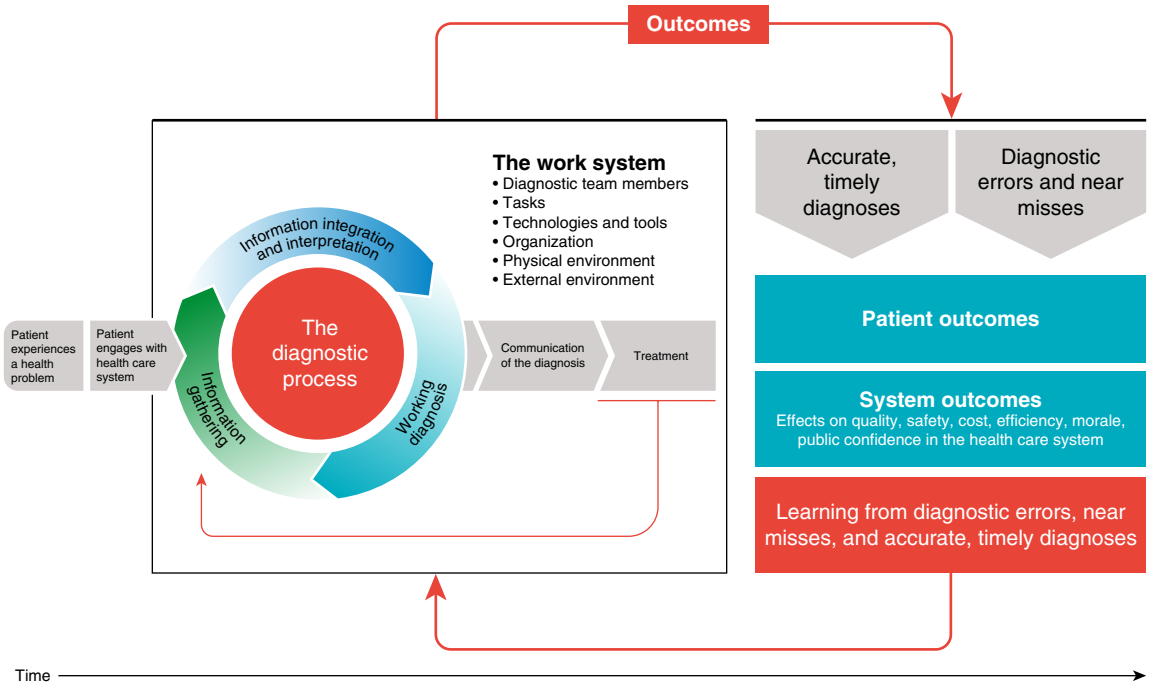


Fig. 5.4 Outcomes from the diagnostic process. (*From National Academies of Sciences, Engineering, and Medicine. 2015. Improving Diagnosis in Health Care https://doi.org/10.17226/21794.*)

in administering liquid medications, particularly when using kitchen spoons rather than dosing syringes. A health literacy–informed pictogram reduces the rates of these errors Additional ambulatory safety threats include delays in diagnosis or treatment caused by mishandling of laboratory or imaging results and failures in care coordination.

Occupational Safety

The provision of healthcare can be a dangerous profession, with injury rates that surpass those of coal miners. The magnitude of this challenge and efforts to improve workplace safety have gained considerable attention over the past several years. Nurses and physicians still typically view a needlestick injury or back strain from lifting a patient as simply "part of the job." A culture of safety should include employee safety, and health systems should have mechanisms for employees to report injuries, near misses, and threats. Focused improvement efforts might include the roll-out of safer needle systems, education on safe processes, and easy access to lifts for larger children with limited mobility. Violence and patient interaction injuries, often from children with psychiatric disease or developmental disabilities, are a growing source of harm to clinicians. Education for clinicians on de-escalation techniques, behavioral specialist engagement in bedside care, and implementation of standardized behavior response teams are active areas of improvement and study as we consider how to best support patients with behavioral needs admitted to the medical unit.

EMERGING AREAS OF SAFETY RESEARCH AND IMPROVEMENT

Safe and Equitable Care

The authors of *Crossing the Quality Chasm* stated that healthcare should target 6 aims for improvement: safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity. These aims are not independent, and we are just beginning to critically examine the relationship between safety and equity. Existing evidence suggests that there are disparities in safety for several groups of pediatric patients, including Black and Latino children, for children whose families do not primarily speak English, and for children on public insurance. In pediatric surgery, one study found that Black children had over three times the odds of dying in the postoperative period, nearly 20% relative greater odds of postoperative complications, and 7% relative higher odds of developing serious adverse events as compared to White children, even while controlling for multiple variables, including racial variation in preoperative morbidity. A systematic review of the evidence in pediatric appendicitis found that social, racial, and economic inequities exist in the rate of misdiagnosis, laparoscopic versus open approach, length of stay, and appendiceal perforation rate. In pediatric severe sepsis, a recent large retrospective study found evidence of an increased odds of death for Black children as compared to White children, particularly in the Western and Southern United States. This study also described longer hospital stays for Hispanic and Black children as compared with White children. Disparities also affect adverse events for hospitalized children, with one multicenter study reporting that hospitalized Latino children experience higher rates of adverse events as compared to non-Latino White children, and publicly insured children experience higher rates of preventable adverse events as compared to those who are privately insured. The Institute for Healthcare Improvement notes that "there can be no quality without equity," and the field of pediatric patient safety is increasingly focused on health equity as a critical and essential outcome measure.

Learning from Patient and Family Partnerships

Another important area of current and growing research involves how healthcare providers can partner with patients and families to improve the safety of care. Families often identify a wide number of errors and safety events that clinicians fail to report. More important than families simply reporting mistakes are early efforts to engage families more broadly and deeply to co-produce healthcare that is efficient, effective, and safe. This is particularly important for the growing population of children with complex chronic disease, for whom family caregivers are critical in identifying deviations from baseline in their children.

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Chapter 6

Ethics in Pediatric Care

Eric Kodish and Bryan A. Sisk

Pediatric ethics is the branch of bioethics that analyzes moral aspects of decisions made relating to the healthcare of children. In general terms, the **autonomy**-driven framework of adult medical ethics is replaced by a **beneficent** paternalism in pediatrics. Pediatric ethics is distinctive because the pediatric clinician has an independent fiduciary obligation to act in a younger child's **best interest** that takes moral precedence over the wishes of the child's parent(s). For older children, the concept of **assent** suggests that the voice of the patient must be heard. These factors create the possibility of conflict among child, parent, and clinician. The approach to the ethical issues that arise in pediatric practice *must* include respect for parental responsibility and authority balanced with a child's developing capacity and autonomy. Heterogeneity of social, cultural, and religious views about the role of children adds complexity.

Additional features of ethical decision-making include **nonmaleficence** (do no harm) and **justice** (treating patients with the same condition equally).

ASSENT AND PARENTAL PERMISSION

The doctrine of *informed consent* has limited direct application to children and adolescents who lack decisional capacity. The capacity for informed decision-making in healthcare involves the ability to understand and communicate, to reason and deliberate, and to analyze conflicting elements of a decision using a set of personal values. The age at which a competent patient may legally exercise voluntary and informed consent for medical care varies from state to state, and there may be exceptions related to specific conditions (sexually transmitted infections, family planning, drug or alcohol abuse).

In contrast to decisions about one's own care, a parent's right to direct a child's medical care is more limited. For this reason, the term *parental consent* is misleading. The concept of parental permission (rather than consent) reflects a *surrogate* or *proxy* decision made by a parent on behalf of a child. It is constrained by the child's best interest, even if this places the clinician in conflict with the parent. In any given instance, the decision of what is or is not in a child's best interest may be difficult, especially given the diverse views of acceptable child rearing and child welfare. Parents are (and should be) granted wide discretion in raising their children. In cases involving a substantial risk of harm, the moral focus should be on avoiding or preventing harm to the child, not on a parental right to decide. Although the term *best interests* may be too high of a threshold requirement, a minimum standard of *basic interests* is ethically obligatory.

Respect for children must account for both a child's vulnerability and developing capacity. This respect encompasses both the protective role of parental permission and the developmental role of **child assent** (the child's affirmative agreement). Understanding the concept of assent is one of the major conceptual challenges in pediatric ethics. The **dissent** (or disagreement) of a child is the opposite of assent and is also morally relevant. Pediatric ethics *requires* clinicians and parents to override a child's dissent when a proposed intervention is essential to the child's welfare. Otherwise, assent should be solicited and dissent honored. In seeking younger children's assent, a clinician should help them understand their condition, tell them what they can expect, assess their understanding and whether they feel pressured to assent, and solicit their willingness to proceed. All efforts must be made to delineate situations in which the test or procedure will be done regardless of the child's assent/dissent, and in such cases the charade of soliciting assent should be avoided. There is an important distinction between soliciting assent and respectfully informing a child that a test or procedure will take place regardless of the child's decision. Optimally, an educational process can transpire (if time allows) to gain the trust and assent of the child-patient. When this cannot occur, pediatric ethics requires that clinicians apologize to a child for acting to override dissent.

Older children or adolescents (<18 years) may have the cognitive and emotional capacity to participate fully in healthcare decisions. If so, the adolescent should be provided with the same information given to an adult patient. In such situations the patient may be able to provide informed consent ethically but not legally. The adolescent's parent(s) remain in a guiding and protective role. The process of communication and negotiation will be more complex should disagreement arise between the parent and adolescent. Pediatricians can be effective intercessors when these situations arise, making use of communication skills in a respectful way that uses an ethical framework.

TREATMENT OF CRITICALLY ILL CHILDREN

Infants, children, and adolescents who become critically ill may recover fully, may die, or may survive with new or increased limitations of function. Uncertainty about outcomes can make planning goals of care difficult or, if misunderstandings among patient, families, and medical staff occur, may drive conflict over treatment proposals. *Ethical issues* that arise during critical illness include balancing benefits, burdens, and harms of therapy in the face of uncertainty; maintaining a helpful degree of transparency and communication about medical standards of care at an institution; understanding and respecting religious and cultural differences that affect requests for or refusal of treatments; defining limits of therapy based on assessments of medical futility; recognizing the moral equivalence of not starting an ineffective treatment and stopping (although the two acts may seem very different to families and even to clinicians); and controversies such as withholding medically administered nutrition and hydration.

Transitioning the Goals of Care

Most acutely ill children who die in an intensive care unit do so after a decision has been made to forgo or withdraw **life-sustaining medical treatment (LSMT)**, and the same may apply in the chronically ill population. LSMT is justified when the anticipated benefit outweighs the burdens to the patient; it is important to note that the availability of technology does not in and of itself obligate its use. Decisions to use, limit, or withdraw LSMT should be made after careful consideration of all pertinent factors recognizable by both family and medical staff, including medical likelihood of particular outcomes, burdens on the patient and family, religious and cultural decision-making frameworks, and input by the patient when possible (Table 6.1). Although fear of legal repercussions may sometimes drive treatment and medical advice, ultimately decisions should be based on what is thought to be best for the patient.

The concept of **futility** has been used to support unilateral forgoing of LSMT against the wishes of patients and families by holding that clinicians should not provide futile (or useless) interventions. If *medical futility* is defined narrowly as the impossibility of achieving a desired physiologic outcome, forgoing a particular intervention is ethically justified. However, this approach may not adequately engage professionals and families in understanding facts and values that might allow the same therapy to reach other goals and may leave medical and family stakeholders in permanent conflict. Guidance from critical care groups recommend restricting use of the word *futility* to situations of strict physiologic futility, and instead use process guidelines to evaluate and manage situations of *potentially inappropriate treatment*. If agreement cannot be reached through clear and compassionate communication efforts, further input should be sought from an ethics consultant or committee.

Communication about life-threatening or life-altering illness is challenging and requires skills learned through both modeling and practice. These *skills* include choosing a setting conducive to what may become one or more long conversations; listening carefully to children's and families' hopes, fears, understanding, and expectations; explaining medical information and uncertainties simply and clearly without complicated terms and concepts; conveying concern and openness to discussion; and being willing to share the burdens of decision-making with families by giving clear recommendations. Discussing difficult topics with children requires an understanding of child development and can be aided by professionals such as child psychologists or child life specialists. Such conversations and their outcomes have a major impact on the future care of the patient, on

Table 6.1 Approach to Termination of Medical Treatments for Adults (≥18 yr) and Children

CONSIDERATION	DISCUSSION
Is there a legal right to refuse medical interventions?	**YES.** The U.S. Supreme Court declared that competent patients ≥18 yr have a constitutionally protected right to refuse unwanted medical treatments. **NO.** In neonates and children, if the treatment is in the best interest of the child, the family cannot refuse beneficial treatments (see later).
What interventions can be legally and ethically terminated?	Any and all interventions (including respirators, antibiotics, pacemakers, ECMO, intravenous or enteral nutrition and hydration) can be legally and ethically terminated.
Is there a difference between withholding life-sustaining interventions and withdrawing them?	**NO.** The consensus is that there is no legal or ethical difference between withholding and withdrawing medical interventions. Stopping a treatment once begun is just as ethical as never having started it.
Whose view about terminating life-sustaining interventions prevails if there is a conflict between the family and physician?	If continued treatment is not beneficial (futile), there is no obligation to continue such care. At times, involvement of an ethics committee or the courts is necessary. In most circumstances, the parents agree with the healthcare team (shared decision-making).
Are advance care directives legally enforceable?	**YES.** As a clear expression of the patient's wishes, they are a constitutionally protected method for patients to exercise their right to refuse medical treatments. In almost all states, clear and explicit oral statements are legally and ethically sufficient for decisions about withholding or withdrawing medical interventions. This is true for patients over 18 yr old. Mature, competent adolescents (≥16 yr) may provide assent and consent to refuse care, but this is not universally accepted.

ECMO, Extracorporeal membrane oxygenation.
Modified from Emanuel EJ. Bioethics in the practice of medicine. In: Goldman L, Schafer AI (eds). *Goldman-Cecil Medicine*. 26th ed. Philadelphia: Elsevier; 2020: Table 2.2.

families, and on medical staff. For this reason, ongoing evaluation of goals and communication about them is needed with families and within complex medical teams as the course of the illness unfolds.

Experts recognize that good medical care involves providing for communication, symptom management, and a range of supportive services from the onset of acute illness. In this way, if an illness proves to be life-limiting despite intensive therapies, the elements of palliative care are already in place. This concept has had difficulty gaining traction, especially in critical care settings, because of the mistaken conflation of broadly defined palliative measures with hospice care. **Palliative care** interventions focus on the relief of symptoms and conditions that may detract from quality of life regardless of the impact on a child's underlying disease process, and as such are important whether care is focused on cure or on transitioning to end-of-life care (see Chapter 8). Some interventions regarded as life-sustaining, such as chemotherapy, may be ethically acceptable in the end-of-life setting if their use decreases pain and suffering.

Withholding and Withdrawing Life-Sustaining Treatment

Limitation of interventions or withdrawal of existing therapies is ethically permissible if congruent with a plan of care focused on **comfort** and **improved quality** at the end of life rather than cure. The prevailing view in Western medical ethics is that there is no moral distinction between withholding or withdrawing interventions that are not medically indicated (see Table 6.1). Uncertainty in predicting a child's response to treatment may drive the initiation and continuation of interventions that are subsequently determined to be no longer aligned with the goals of care. It is important to continually evaluate the results of these treatments and the evolution of the illness to recognize whether such interventions continue to be the best medical and moral choices. Maintaining the focus on the child rather than on the interests of parents or medical staff should be the primary driver of decision-making.

The decision about whether to attempt **cardiopulmonary resuscitation** (CPR) may become an issue to discuss with parents of children living with life-threatening or terminal conditions. All elements of end-of-life care approaches, including resuscitation status, should be supportive of agreed-on goals of care. It is imperative that decisions and plans are effectively communicated to all caregivers in order to avoid denying medically effective interventions and measures to ensure comfort. Orders about resuscitation status should clarify the plan regarding intubation and mechanical ventilation, the use of cardiac medications, chest compressions, cardioversion, blood products, antibiotics, and dialysis. Because goals of care may change over time, a medical order regarding resuscitation is not irrevocable. Clinicians may assume that the absence of a **do-not-attempt-resuscitation (DNAR)** order obligates them to perform CPR. This action may not be ethically obligatory if resuscitative efforts will not achieve the desired physiologic end-point. In all cases, treatments should be tailored to the child's clinical condition, balancing benefits and burdens to the patient. Resuscitation should not be performed solely to mollify parental distress at the tragic time of the loss of their child.

Artificial Hydration and Nutrition

Issues surrounding withholding or withdrawing artificial hydration and nutrition are controversial, and interpretations are affected by parental religious and medical beliefs. Any adult or child who is fully dependent on the care of others will die as a result of not receiving hydration and nutrition. Case law has supported the withholding of artificially administered nutrition and hydration in the setting of adult vegetative or permanently unconscious patients who can be shown to have previously expressed a wish not to be maintained in such a state. This requires a valid advance directive or for a surrogate decision maker to speak on behalf of the patient's known wishes. Because infants and many children have not reached a developmental stage in which such discussions would have been possible, decisions about stopping artificially administered nutrition and hydration as a limitation of treatment are more problematic. These decisions should be based on what families and caregivers decide best support comfort. In the child who is imminently dying, unaware of hunger, does not tolerate enteral feedings, and in whom family and staff agree that IV nutrition and hydration only prolong the dying process, it may be ethically permissible to withhold or withdraw these treatments based on a benefit-burden analysis.

The Doctrine of Double Effect

Treatment decisions at the end of life may include limitations of certain LSMT or may involve the use of analgesic or sedative medications that some fear may shorten life, thereby causing death. The doctrine of double effect (**DDE**) holds that an action with both good and bad effects is morally justifiable if the good effect is the only one intended and the bad effect is foreseen and accepted, but not desired. In pediatrics, DDE is most commonly applied in end-of-life cases when upward titration of medication (opiates) necessary to relieve pain, anxiety, or air hunger can be expected to result in a degree of respiratory depression. In such cases, meeting a clinician's obligation to relieve suffering is the intended effect, and this

obligation to the patient outweighs the acknowledged but unavoidable side effect. Choosing medications that adequately relieve symptoms with minimal adverse effects would be ethically preferable, but absent these options, the obligation to provide comfort at the end of life outweighs the foreseeable occurrence of unavoidable side effects. Hastening death as a primary intention is not considered to be morally acceptable.

Providing pain medication guided by the DDE should not be confused with active euthanasia. The distinction is clear:

- In **active euthanasia**, causing death is chosen as a means of relieving the symptoms that cause suffering.
- Under DDE, adequate management of pain, anxiety, or air hunger is recognized as an obligation to dying patients and is provided by careful titration of medications in response to symptoms. If death occurs sooner as a result, this is accepted.

In both cases the patient dies, and in both cases suffering ends, but immediate death is the intended consequence only in the case of euthanasia. Codes of ethics and legislation in many states support the obligation to provide pain and symptom relief at the end of life, even if this requires increasing doses of medication.

NEONATAL ETHICS

As neonatal care has evolved, the limits of viability of extremely premature infants are continuing to change. This introduces new elements of uncertainty to decision-making, often in emotionally fraught circumstances such as a precipitous premature delivery. In cases of uncertain prognosis, parental desires should determine the decision-making, while clinicians should help parents recognize when treatments are inappropriate; this should result in a shared decision-making approach to developing plans of care.

The federal **Child Abuse Prevention and Treatment Act** of 1984 (CAPTA), which became known as "Baby Doe Regulations," required state child protective services agencies to develop and implement mechanisms to report to a specific government agency treatment that the reporter believed was withheld from infants on the basis of disability. Exceptions were (1) an infant is chronically and irreversibly comatose; (2) if providing a treatment would merely prolong dying, would not be effective in ameliorating or correcting all the infant's life-threatening conditions, or would be futile in terms of the infant's survival; and (3) if the treatment would be virtually futile and inhumane. This legislation pertains *only* to infants and is intended to prevent discrimination on the basis of disability alone. One consequence of the legislation was a shift from potential undertreatment to widespread overtreatment (LSMT that does not serve the interests of the child) of severely disabled newborns. As parental involvement in decision-making is again taking a more central role, and as palliative care approaches in infants have become more available and skilled, balanced approaches to valuing the lives of disabled infants should be considered. Understanding institutional, regional, state, and national regulations related to care of infants is important in order to practice within regulatory frameworks while respecting the values of the family and pursuing the interests of the patient.

Active euthanasia of severely suffering disabled newborns has been legalized in The Netherlands and Belgium, using protocols designed to minimize the risk of abuse and maximize transparency. It is currently illegal in the United States, and although controversy surrounds the subject, the predominant view is that active euthanasia is not ethically acceptable in the care of infants and children, instead favoring palliative treatment (including pain management) and limiting escalation of treatment (see Chapter 8).

DECLARING DEATH AND ORGAN DONATION

Donation of solid organs necessary to support life can occur after a patient is declared dead based on either irreversible cessation of function of the brain and brainstem (death by neurologic criteria, or *brain death*) or a predetermined period of cardiac asystole called *circulatory death* (see Chapter 83). To avoid a potential conflict of interest by surgeons or others caring for a potential organ recipient, the request for organ donation should be separated from the clinical discussion of either brain death or withdrawal of LSMT. Although clinicians may be the first to enter discussion about death and organ donation with family members during conversations about outcomes and options, detailed discussion of organ donation should be done by other individuals who are specifically trained for this purpose. This decoupling of clinical decision-making from a request for organ donation by trained individuals, perhaps by providing families with expert information without a perceived conflict of interest, has been associated with improved donation rates.

Death by Neurologic Criteria

Death by neurologic criteria (**DNC**), commonly referred to as brain death (**BD**), may be difficult for families to understand when the child appears to be breathing (although on a ventilator), pink, and warm to the touch and when language such as "life support" is used at the bedside by staff. Studies also document clinician misunderstanding of the diagnosis of **BD/DNC**. For these reasons, strict criteria adhering to nationally accepted guidelines must be used to determine when irreversible cessation of brain and brainstem function (coma, brainstem areflexia, apnea) has occurred and adequately document these findings (see Chapter 83).

RELIGIOUS OR CULTURAL OBJECTIONS TO TREATMENT

Differences in religious beliefs or cultural norms may lead to conflict among patients, families, and medical caregivers over the approach to medical care. Pediatricians need to remain sensitive to and maintain an attitude of respect for these differences yet recognize that an independent obligation exists to provide safe and effective medical treatment to the child. An adult with decision-making capacity is recognized as having the right to refuse treatment on religious or cultural grounds, but children who have not yet developed this capacity are considered a vulnerable population with a right to treatment. In situations that threaten the life of the child or that may result in substantial harm, legal intervention should be sought if reasonable efforts toward collaborative decision-making are ineffective. If a child's life is imminently threatened, medical intervention is ethically justified despite parental objections.

PEDIATRIC ETHICS COMMITTEES AND ETHICS CONSULTATION

Most hospitals have *institutional ethics committees* to assist with policy development, education, and case consultation. When these committees serve institutions caring for children, they may be referred to as *pediatric ethics committees*. Because of the important differences in approach between adult and pediatric ethics, member expertise on this committee should include those with special insight into the unique ethical issues arising in the care of children. Such committees generally provide ethics consultation advice without mandating action or being determinative. For the vast majority of decisions involving the medical treatment of children (including forgoing LSMT), pediatric clinicians and parents are in agreement about the desirability of the proposed intervention. Because of the ethical importance of assent, the views of older children should also be given considerable weight.

Pediatric ethics committees typically perform at least three different functions: (1) the drafting and review of institutional policy on such issues as DNAR orders and forgoing LSMT, (2) the education of healthcare professionals, patients, and families about ethical issues in healthcare, and (3) case consultation and conflict resolution. Although the process of *case consultation* may vary, ideally the committee (or consultant) should adopt a collaborative approach that uncovers all the readily available and relevant facts, considers the values of those involved, and balances the relevant interests, while arriving at a recommendation based on a consistent ethical analysis. One helpful approach involves consideration of the 4 following elements: (1) medical indications, (2) patient preferences, (3) quality of life, and (4) contextual features. Another framework based on principles would suggest attention to respect for persons, beneficence/nonmaleficence, and justice.

Pediatric ethics committees often play a constructive role when parents and medical staff cannot agree on the proper course of action. Over the past several decades, these committees have acquired considerable influence and are increasingly recognized by state courts as an important aid in decision-making. The membership, policies, and procedures of a pediatric ethics committee should conform to accepted professional standards.

NEWBORN SCREENING

The *Oxford Dictionary of Public Health* defines screening as "the identification of a previously unrecognized disease or disease precursor, using procedures or tests that can be conducted rapidly and economically on large numbers of people with the aim of sorting them into those who may have the condition(s) … and those who are free from evidence of the condition(s)." Several programs, such as newborn screening for inborn errors of metabolism (see Chapter 104; e.g., phenylketonuria and hypothyroidism), are rightly counted among the triumphs of contemporary pediatrics. The success of such programs sometimes obscures serious ethical issues that continue to arise in proposals to screen for other conditions for which the benefits, risks, and costs have not been clearly established. Advances in genetics and technology have led to exponential growth in the number of conditions for which screening programs might be considered, with insufficient opportunity to study each proposed testing program (see Chapter 95).

The introduction of screening efforts should be done in a carefully controlled manner that allows for the evaluation of the costs (financial, medical, and psychologic) and benefits of screening, including the effectiveness of follow-up and treatment protocols. New programs should be considered *experimental* until the risks and benefits can be carefully evaluated. Screening tests that identify candidates for treatment must have demonstrated sensitivity, specificity, and high predictive value, lest individuals be falsely labeled and subject to possibly toxic treatments or to psychosocial risks. As newborn screening tests are being developed, parents should be given the opportunity to exercise informed parental permission or refusal. However, once a particular screening test has been clearly demonstrated to benefit the individual or public health, a formal, active parental permission process may not be ethically obligatory.

A persistent ethical issue is whether screening should be (1) voluntary ("opt in"), (2) routine, with the ability to "opt out" or refuse, or (3) mandatory. A **voluntary** approach entails an informed decision by parents before screening. Concern is often expressed that seeking parental permission is ethically misguided for tests of clear benefit, such as phenylketonuria screening, because refusal would constitute neglect. **Routine** testing with an opt-out approach requires an explicit refusal of screening by parents who object to this intervention. The principal ethical justification for **mandatory** screening is the claim that society's obligation to promote child welfare through early detection and treatment of selected conditions supersedes any parental right to refuse this simple and low-risk medical intervention. Parental permission is clearly required when there is a research agenda (i.e., for incorporating experimental tests into established screening programs).

GENETICS, GENOMICS, AND PRECISION MEDICINE

Genetics refers to the study of particular genes, and **genomics** describes the entirety of an individual's genetic material. Genomics has been made possible by technologic advances that allowed the rapid and inexpensive sequencing now used in clinical care. The development of **precision medicine** is in large part predicated on genomic science and may have a major impact on the practice of pediatrics in the future. Efforts to undertake whole-genome sequencing of newborns may yield actionable information to benefit the child, but also carry the risk of stigmatization, false positives, and unwanted information that could lead to anxiety and psychologic distress.

Genetic testing of young children for late-onset disorders such as the *BRCA1* and *BRCA2* breast cancer risk genes has also been the subject of some ethical controversy. Knowledge of increased risk status may lead to lifestyle changes that can reduce morbidity and the risk of mortality or may precipitate adverse emotional and psychologic responses and discrimination. Because many adults choose not to be tested for late-onset disorders, one cannot assume that a child would want or will benefit from similar testing. Genetic testing of young children for late-onset disorders is generally inappropriate unless such testing will result in interventions that have been shown to reduce morbidity and mortality when initiated in childhood. Otherwise, such testing should be deferred until the child has the capacity to make an informed and voluntary choice.

Precision medicine promises to enhance treatment and public health outcomes in the future. Yet the success of precision medicine will depend on whose data are used to develop and refine artificial intelligence algorithms that will inform care. A large body of literature has begun to explore racial and ethnic disparities in precision medicine, with the goal of ensuring advances will benefit all people. However, children represent another group that is at risk of exclusion from these benefits. Historically, the rarity of many childhood illnesses, protective regulations, and financial disincentives have limited the development of effective treatments for many childhood diseases. Legislation such as the "Research to Accelerate Cures and Equity for Children Act" (RACE Act) has begun to mandate greater representation of children in clinical trials. If similar steps are not taken in pediatric precision medicine, we run the risk of creating a new generation of therapeutic orphans.

ADOLESCENT HEALTHCARE

Adolescent Assent and Consent

Many adolescents are more like adults than children in their capacity to understand healthcare issues and to relate them to their life goals (see Chapter 150). Teenagers may lack legally defined competency, yet they may have developed the capacity to meet the elements of informed consent for many aspects of medical care (see Chapter 151). There are also public health reasons for allowing adolescents to consent to their own healthcare with regard to reproductive decisions, such as contraception, abortion, and treatment of sexually transmitted infections. Strict requirements for parental permission may deter adolescents from seeking healthcare, with serious implications for their health and other community interests.

Counterbalancing these arguments are legitimate parental interests to maintain responsibility and authority for child rearing, including the opportunity to influence the sexual attitudes and practices of their children. Others claim that access to treatment such as contraception, abortion, or needle exchange programs implicitly endorses sexual activity or drug use during adolescence. Pediatricians should not impose their own moral beliefs in these disputes. Rather, they should provide unbiased evidence-based information and nonjudgmental support. One guiding principle should be encouragement of children and adolescents to begin taking responsibility, with guidance, for their own health. This requires some input from parents or guardians but also some privacy during decision-making as adolescents achieve developmentally anticipated separation from parental control.

Communication, Privacy, and Confidentiality

Exchanging information is a core function of communication in pediatric and adolescent care. As adolescents mature, their need to exchange information about sensitive topics can increase, complicating the triadic clinician-parent-child relationship. For example, adolescents might wish to start oral contraception or seek treatment for a sexually transmitted infection without their parents' knowledge. The confidentiality of conversations about reproductive health and sexually transmitted infections between adolescents and clinicians is often protected by state laws, although the scope of protections in these laws varies widely. A recent federal law that mandates increased transparency in medical care will further complicate this sensitive communication.

The 21st Century Cures Act included a rule that requires healthcare organizations to provide electronic health information (EHI) to patients in easily accessible platforms. This mandate went into effect in April 2021. As a result of this law, adolescents now have access to their EHI. For preadolescent patients, healthcare organizations provide proxy access to parents. When children reach adolescence, approaches to provision of EHI access vary greatly. Some sites allow parental access to adolescent EHI that has been filtered for confidential information. Other sites revoke parental access, but allow adolescents the option of permitting proxy consent. Still other sites permanently revoke parental access once a child has reached adolescence. This new transparency will likely provide benefits, but could also generate new ethical risks to preserving the confidentiality of adolescent patients. Pediatricians must be cognizant of this tension when creating clinical documentation that might be visible to parents and adolescent patients.

Chronic Illness

The normal process of adolescent development involves gradually separating from parents, establishing self-confidence, asserting individuality, developing strong peer relationships, solidifying an ability to function independently outside the family, and taking on increasing autonomy in healthcare decisions. Most developmentally typical children older than age 14 years understand the implications of well-explained medical options as well as the average adult, and their input into their own care should be respected. For children living with chronic illness, the ability to make medical decisions for themselves may either occur earlier than for those who have been previously healthy or may occur later if, because of illness, they have not been able to achieve normal developmental milestones or psychologic maturity. The clinician's role involves assessment of the individual adolescent patient's ability to understand the medical situation, to support the patient's efforts to express wishes regarding medical treatment, to value and encourage parental support and involvement, and to foster cooperation and mutual understanding. This may be difficult in situations in which parents and adolescents disagree about life-sustaining treatments such as organ transplantation or chemotherapy, but many such conflicts may be resolved by exploring the reasons for the disagreement. Overriding an adolescent's wishes should be done very infrequently and only after careful consideration of the potential consequences of unwanted interventions.

Decisions in Terminally Ill Adolescents

Most adolescents share end-of-life decision-making with family members, although communication may be challenging because of a growing sense of independence. Open communication and flexibility about treatment preferences may help teens cope with fears and uncertainties. Development of an age-appropriate advance directive may support the patient's emerging autonomy by clarifying the adolescent's wishes while fostering a collaborative process among the patient, family, and medical caregivers. From the time of diagnosis of a life-threatening condition through the end-of-life phase, children should be included in a developmentally tailored process of communication and shared decision-making that builds a foundation of mutual respect and trust. Some experts believe that most adolescents are not yet fully capable of making a decision to forgo life-sustaining treatment. Careful case-by-case evaluation is required to make this determination, and assistance from developmental psychologists and ethics consultants may be helpful.

RESEARCH

The central ethical challenge of pediatric research is the need to balance protection of children from research risk against the ethical imperative of conducting studies to better the lives of future children. *Research* is defined in the federal regulations as "a systematic investigation designed to develop or contribute to generalizable knowledge." For any research to be performed, the risks should be minimized and reasonable with respect to any anticipated benefits to the participants and the importance of the resulting knowledge. That some children derive a direct benefit from participation in research must also be considered, making it important to distinguish research with the prospect of direct benefit from nontherapeutic pediatric research. *Because children are a vulnerable population, there are restrictions on the research risks to which a child may be exposed,* in contrast to the risk level acceptable for research with consenting adults**.** These restrictions function by limiting the type of research that institutional review boards (IRBs) are permitted to approve and by specifying the conditions under which parents have the moral and legal authority to permit a child to participate in research.

Nontherapeutic research in children is the most ethically controversial because it holds no expected direct benefit for the individual. The prohibition against using a person (especially a child) solely as a means to an end has led some to argue that children should *never* be used in nontherapeutic research. The more widely held opinion is that children may be exposed to a limited degree of risk with IRB approval, parental permission, and assent if the child is capable. The federal regulations allow healthy children to participate in minimal-risk research regardless of the potential benefit to the child. More controversially, the regulations also state that children with a disorder or condition may be exposed to slightly more than minimal risk in nontherapeutic research if the child's experience is similar to everyday life with the condition and the anticipated knowledge is of vital importance for understanding the condition.

In pediatric research with the prospect of direct benefit, the risks must be justified by the anticipated benefit to the child, and the balance of anticipated benefit to the risk should be at least as favorable as that presented by available alternatives. *In our opinion, the welfare of an individual child must always come before the scientific goals of the research study.*

U.S. regulations for the protection of human research participants rest on two foundations: (1) independent review of the ethics and science of the research by an IRB **before** (2) voluntary and informed consent of the participant. Although it is not amenable to regulation, the *integrity* of the investigator is probably the most important element contributing to the protection of human research participants. The standard for informed consent in a research setting is higher than for clinical care because the risks and benefits are typically less clear, the investigator has a conflict of interest, and humans have historically been subjected to unauthorized risks when strict requirements for consent were not respected.

Adolescents who are competent may sometimes consent to be research participants. Younger children may participate in a process of assent, but this does not imply that a child's signature on an assent document is necessarily a legal or ethical requirement. Children should be given the opportunity to dissent, particularly for nontherapeutic research, when there cannot be a claim that participation is in the child's interest. In the United States, national regulations require that reasonable efforts be made at least to inform children who are capable of understanding that participation is *not* part of their care, and therefore they are free to refuse to participate. In the rare case that the research offers a direct benefit to the child that would not otherwise be available, the regulations do not require child assent but only parental permission.

In addition to the protection that informed consent or parental permission is intended to provide, virtually all research involving humans in the United States is reviewed by an IRB, as required by federal regulations for institutions receiving federal research funds and for drug research regulated by the U.S. Food and Drug Administration. For research that carries more than a minor increase over minimal risk without prospect of benefit to the child such that a local IRB cannot provide approval, there is a process for federal review of research that "presents a reasonable opportunity to further the understanding, prevention, or alleviation of a serious problem affecting the health or welfare of children." Ultimately, the U.S. Secretary of Health and Human Services has the authority to approve such research.

JUSTICE AND PEDIATRIC ETHICS

The most serious ethical problem in U.S. healthcare may be *inequality* in access to healthcare. Children are particularly vulnerable to this disparity, and pediatricians have a moral obligation to advocate for children as a class. Because children do not vote and do not have financial resources at their disposal, they are subject to a greater risk of being uninsured or underinsured. This lack of adequate and affordable healthcare has serious consequences in terms of death, disability, and suffering. The per capita proportion of healthcare funding spent on adults greatly exceeds that spent on children, and Medicare is available to all adults who turn 65 years old, whereas Medicaid is limited to those beneath a specific income level. Pediatricians should be familiar with policy issues around the economics of child healthcare so that they will be better able to advocate for their own patients.

Beyond access to healthcare, structural social inequalities also have profound impacts on child health and well-being. Systemic racism and structural disadvantages can affect every aspect of pediatric care, from infant mortality and neonatal care delivery to asthma outcomes and surgical complications. Furthermore, social inequality and adverse childhood experiences (ACEs) have been linked to greater incidence of chronic diseases, substance abuse, increased encounters with the justice system, and lower executive functioning. Pediatricians should take active steps to acknowledge and attempt to mitigate the effect of these inequalities on their patients through individual, local, and national advocacy efforts.

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Chapter 7

Complementary Therapies and Integrative Medicine

Paula M. Gardiner and Caitlin M. Neri

Integrative medicine focuses on promoting physical, mental, emotional, spiritual, social, and educational well-being in the context of a medical home in a healthy family and community. The foundations of integrative medicine are health-promoting practices such as optimal nutrition and dietary supplements to prevent deficiencies, avoidance of addictive substances (e.g., nicotine, illicit drugs), physical activity, adequate sleep, a healthy environment, and supportive social relationships. Evidence-based **complementary therapies** such as dietary supplements, massage, chiropractic, other forms of bodywork, yoga, meditation practices, hypnosis, guided imagery, biofeedback, and acupuncture may also be used.

Not including multivitamins and mineral supplements such as iron and calcium, an estimated 10–40% of healthy children and >50% of children with chronic conditions use integrative medicine in the United States. The prevalence could be even higher because these treatments usually occur without disclosure to the children's primary care physician. Common therapies include dietary supplements, deep breathing, guided imagery, meditation, biofeedback, hypnosis, yoga, acupuncture, massage, and aromatherapy.

Use of complementary therapies is most common among youth with chronic, incurable, or recurrent conditions such as cancer, depression and other mental health conditions, asthma, autism, headaches, abdominal pain, and other chronic painful conditions. In a 2017 study of freestanding children's hospitals, 92% offered complementary services, 38% had a specific complementary center on-site, and 60% had policies related to supplement use during hospitalization. Integrative therapies are being used in pediatric cancer symptom management and chronic pain clinics. Practice often includes supplements (e.g., probiotics) and mind-body techniques (e.g., hypnotherapy, biofeedback) with traditional medical management for these common pediatric conditions.

DIETARY SUPPLEMENTS

Under the 1994 U.S. Dietary Supplement Health and Education Act, a **dietary supplement** is a product taken by mouth that contains a *dietary ingredient* intended to supplement the diet. These may include vitamins, minerals, herbs or other botanical, amino acids, and substances such as enzymes, organ tissues, glands, and metabolites. Dietary supplements are the most frequently used complementary therapies for children and adolescents (Table 7.1). Some uses are common and recommended, such as vitamin D supplements for breastfed infants and probiotics to prevent antibiotic-associated diarrhea, whereas other uses are more controversial, such as using herbal products to treat otitis media.

In the United States, dietary supplements do not undergo the same stringent evaluation and postmarketing surveillance as prescription medications. Although they may not claim to prevent or treat specific medical conditions, product labels may make *structure-function* claims. A label may claim that a product "promotes a healthy immune system," but it may not claim to cure the common cold.

According to the 2017–2018 National Health and Nutrition Examination Survey (NHANES), 34% of children and adolescents used any dietary supplement in the past 30 days, with multivitamin-mineral products the most common (24%). Use of dietary supplements is most common among children whose families have higher income and education and whose parents use supplements, among older children, and among those with chronic conditions.

Despite this widespread use, many patients and their parents who use dietary supplements do not talk with their physician about their use. Several guidelines have called for more complete dietary supplement history taking by healthcare professionals. The Joint Commission recommends that this information be included in the medication reconciliation process.

DIETARY SUPPLEMENT SAFETY

Dietary supplements may have safety issues in children, but toxicity is much less common with nonprescription dietary supplements than with prescription medications. Toxicity depends on dose, use of other therapies, and the child's underlying medical condition (see Table 94.20). Current use of a dietary supplement (e.g., ephedra for weight loss) may not reflect its traditional use (e.g., ephedra as a component of a traditional Chinese medicine tea in small doses to improve allergic or respiratory symptoms). Moreover, herbs that are apparently safe for most adults may be more hazardous in specific conditions (e.g., newborns, patients with impaired renal or hepatic function), under special circumstances (e.g., after organ transplantation or other surgery), or when combined with prescription medications. Some natural products are toxic in and of themselves. Even when a product is safe when used correctly, it can cause mild or severe toxicity when used incorrectly. Although peppermint is a commonly used and usually benign gastrointestinal spasmolytic included in after-dinner mints, it can exacerbate gastroesophageal reflux.

Table 7.1 Commonly Used Dietary Supplements in Pediatrics

PRODUCT	USES
VITAMINS	
B_2 (riboflavin)	Migraine headache prophylaxis
B_6 (pyridoxine)	Pyridoxine-dependent epilepsy; neuropathy; nausea associated with pregnancy
B_9 (folate)	Prevention of neural tube defects
D	Prevention of rickets; treatment of vitamin D deficiencies
Multivitamins	General health promotion
MINERALS	
Iodine (salt)	Prevent goiter and intellectual disability
Iron	Prevent and treat iron-deficiency anemia
Magnesium	Constipation, asthma, migraine prevention
Zinc	Diarrhea in nutrient-poor populations
HERBS*	
Aloe vera	Mild burns
Chamomile	Mild sedative, dyspepsia
Echinacea	Prevention of upper respiratory infections
Ginger	Nausea
Lavender (aromatherapy)	Mild sedative
Peppermint	Irritable bowel syndrome
Tea tree oil	Antibacterial (acne remedies), pediculicide (lice)
OTHER	
Melatonin	Insomnia
Omega-3 fatty acids	ADHD, allergies, inflammation, anxiety and mood disorders
Probiotics	Antibiotic-associated diarrhea; *Clostridium difficile*–associated diarrhea; constipation; irritable bowel syndrome; pouchitis; inflammatory bowel disorders

ADHD, Attention-deficit/hyperactivity disorder.
*See text; potentially useful evidence base not established for many herbs.

Although there are good manufacturing practices for dietary supplements in the United States, dietary supplement labels might not accurately reflect the contents or concentrations of ingredients. Because of natural variability, variations of 10-fold to 1,000-fold have been reported for several popular herbs, even across lots produced by the same manufacturer. Herbal products may be contaminated with pesticides or microbial agents or toxins, or the wrong herb may be misidentified during harvesting. Products from some countries (e.g., Ayurvedic products from South Asia) might contain toxic levels of mercury, cadmium, arsenic, or lead, either from unintentional contamination during manufacturing or from intentional additions by producers who believe that these metals have therapeutic value. Approximately 30–40% of Asian patent medicines include potent pharmaceuticals, such as analgesics, antibiotics, hypoglycemic agents, or corticosteroids; typically the labels for these products are not written in English and do not note the inclusion of pharmaceutical agents. Even conventional mineral supplements, such as calcium, have been contaminated with lead or had significant problems with product variability.

Many families use supplements concurrently with medications, posing hazards of interactions (Table 7.2). Using the same principles of drug-drug interactions can help determine if a supplement-drug interaction is a concern. For example, St. John's wort induces CYP3A4 activity of the cytochrome P450 enzyme system and thus can enhance elimination of most drugs that use this pathway, including digoxin, cyclosporine, protease inhibitors, oral contraceptives, and numerous antibiotics, leading to subtherapeutic serum levels.

DIETARY SUPPLEMENT EFFICACY

Evidence about the effectiveness of dietary supplements to prevent or treat pediatric problems is mixed, depending on the product used and condition treated. Some herbal products may be helpful adjunctive treatments for common childhood problems; some herbs have proved helpful for colic (fennel and the combination of chamomile, fennel, vervain, licorice, and balm mint), nausea (ginger), irritable bowel syndrome (peppermint), and diarrhea (probiotics).

MASSAGE AND CHIROPRACTIC

Massage is usually provided at home by parents and in clinical settings by professional massage therapists, physical therapists, and nurses. **Infant massage** is routinely provided in many neonatal intensive care units to promote growth and development in preterm infants. Massage also has been demonstrated to be beneficial for pediatric patients with asthma, insomnia, colic, cystic fibrosis, or juvenile arthritis and patients undergoing cancer therapy. **Massage therapy** is generally safe. Professional massage practice is regulated by state government and may be in the form of a license, registration, or certification. More than 44 states license massage therapists, with licensure being the strictest form of regulation, making it illegal for any nonlicensed professional to practice massage therapy.

Chiropractic healthcare deals with the diagnosis, treatment, and prevention of disorders of the neuromusculoskeletal system and their effects on general health. Currently, >70,000 chiropractors have licensure in the United States, with licensure in all 50 states. Most medical insurance companies cover chiropractic care. Children and families seek chiropractic care for common childhood conditions such as asthma, infantile colic, nocturnal enuresis, constipation, and headache. A consensus update on chiropractic care in children found no evidence for the effectiveness of chiropractic care for such common childhood conditions. With respect to safety, the evidence is also limited; however, published cases of serious adverse events in infants and children receiving chiropractic care are rare. Unfortunately, although rare, complications of cervical manipulation include vertebrobasilar dissection with resultant stroke and rupture of a syringomyelia with resultant paralysis. If children and families are seeking chiropractic care, it is appropriately done following consultation with the child's pediatric primary care provider to ensure patient safety. In addition, chiropractors often give medical advice beyond their expertise; up to 30% believe vaccines have significant side effects.

MIND-BODY THERAPIES

Mind-body therapies such as slow, deep breathing, meditation, guided imagery, biofeedback, hypnosis, tai chi, and yoga are also frequently used complementary therapies in pediatrics. These practices can be learned informally through books, online videos, compact discs, digital video discs, smartphone apps, or classes and in therapeutic sessions with health professionals, such as psychologists and social workers (Table 7.3). Substantial research suggests that such practices can aid in reducing anxiety, insomnia, and stress-related conditions, including migraine headaches and functional abdominal pain. These therapies can also help patients struggling with chronic pain.

ACUPUNCTURE

Modern acupuncture incorporates treatment traditions from China, Japan, Korea, France, and other countries. In the United States, acupuncturists are licensed to practice in 47 states. Acupuncture can be delivered to pediatric patients in hospital and clinic settings to treat a variety of ailments. Acupuncture is particularly useful for children experiencing pain, and acupuncture services are offered alongside conventional medicine and psychology by >50% of North American academic pediatric chronic pain programs. The technique that has undergone the most scientific study involves penetrating the skin

Table 7.2 Common Herbal Dietary Supplement (HDS)–Drug Interactions

HDS	DRUGS	POTENTIAL CONSEQUENCES/REACTIONS
Aloe vera	Glibenclamide (glyburide)	↑ Oral aloe vera gel can cause additive glycemic-lowering effects when taken concurrently with a hypoglycemic agent
Bitter orange	Phenelzine	↑ Risk of hypertensive crisis
Garlic	Ritonavir	↓ Effect of ritonavir
	Saquinavir	↓ Effect of saquinavir
Licorice	Warfarin	↑ Risk of bleeding
Grapefruit	Calcium channel blockers	Grapefruit juice has been found to increase the bioavailability of certain drugs by inhibition of the cytochrome P450 (CYP) 3A4 isozyme in the liver and gut wall
Melatonin	Zolpidem	↑ Sedative effects
Valerian	Alprazolam, phenobarbital	↑ Central nervous system depression
Goldenseal	Inhibition of CYP2D6 and CYP3A4	May affect approximately 50% of common pharmaceutical agents
St. John's wort	Cyclosporine, tacrolimus, warfarin, protease inhibitors, digoxin, theophylline, venlafaxine, oral contraceptives	May decrease drug effectiveness

↓, Decreasing; ↑, increasing.

Table 7.3 Commonly Used Mind-Body Practices in Pediatrics

PRACTICE	USES
Biofeedback	Preventing migraine headaches; reducing stress and anxiety; encopresis/constipation treatment; treatment of stress incontinence; neurofeedback is adjunctive for ADHD
Deep breathing	Relaxation; stress management
Guided imagery	Stress management; anxiety reduction; pain relief
Hypnosis	Correcting habit disorders; preventing headaches; managing pain
Meditation	Stress management; improving concentration
Tai chi	Improving balance, coordination, concentration, and discipline
Yoga	Improving balance, coordination, and concentration

ADHD, Attention-deficit/hyperactivity disorder.

with thin, solid, metallic needles manipulated by hand or by electrical stimulation. Variants include rubbing (**shiatsu**), heat (**moxibustion**), lasers, magnets, pressure (**acupressure**), or electrical currents.

Although pediatric patients may be averse to needles, when approached in a developmentally appropriate way by an acupuncturist trained in pediatrics, children are often amenable to acupuncture and report that it is helpful. Acupuncture can offer significant benefits in the treatment of recurrent headache, anxiety, back and other types of pain, depression, abdominal pain, and nausea. Infections and bleeding are rare but can occur, and more serious complications, such as pneumothorax, occur in <1 in 30,000 treatments.

CANNABIS

Because marijuana has been legalized in many states for both recreational (adult) use and medical use, caregivers and families may inquire about the potential health benefits of cannabis for both children and adults. There are significant safety concerns in adolescents and young adults, because detrimental effects of marijuana on the developing brain have been documented. One systematic review of 90 studies, including 9,441 adolescents and young adults, provided preliminary evidence for functional and structural alterations in frontoparietal, frontolimbic, frontostriatal, and cerebellar regions among adolescent cannabis users.

It is important to note that in some children with severe refractory epilepsy, oral cannabidiol, a nonpsychoactive component in marijuana, improves seizure control. Outside of prescription cannabidiol, the purity and regulation of marijuana and its commercially available component products are variable. Most of the pediatric literature on cannabis describes an increase in accidental ingestions in young children, presumably in association with the increase in products now available for adult use; this is an additional safety risk for pediatricians to consider.

INTERNET RESOURCES

American Academy of Pediatrics Section on Integrative Medicine: https://www.aap.org/en/community/aap-sections/integrative-medicine/about-soim/

Academic Consortium Integrative Medicine and Health: http://www.imconsortium.org/

National Institutes of Health, National Center for Complementary and Integrative Health: https://nccih.nih.gov/

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Chapter 8

Pediatric Palliative Care

Katharine Davidoff, Chelsea Heneghan, Joanne Wolfe, and Christina Ullrich

According to the World Health Organization (WHO), "Palliative care for children is the active total care of the child's body, mind and spirit and also involves giving support to the family. Optimally, this care begins when a life-threatening illness or condition is diagnosed and continues regardless of whether or not a child receives treatment directed at the underlying illness." Provision of palliative care applies to children with a wide variety of serious illnesses, including cancer, cystic fibrosis, complex or severe cardiac disease, neurodegenerative disorders, severe malformations, and trauma with life-threatening sequelae (Table 8.1). Many children who benefit from integration of palliative care approaches have **complex chronic conditions and are supported by advanced medical technology that allows them to live longer**. These children, who often survive health crises followed by the renewed need for rehabilitative and life-prolonging treatments, are best served by a system that is flexible and responsive to changing needs and blended goals of care.

Although often mistakenly understood as synonymous with *end-of-life care,* **the scope and potential benefits of palliative care are applicable *throughout the illness trajectory*.** Palliative care emphasizes ascertaining and aligning with goals of care, which may be congruent with maximal treatment aimed at sustaining or prolonging life, optimization of quality of life, communication, and symptom control.

The mandate of pediatric clinicians to attend to children's physical, mental, and emotional health and development includes the provision of palliative care for those who live with a significant possibility of death before adulthood (Fig. 8.1). As such, all pediatric clinicians benefit from using basic (primary) palliative care principles when approaching the care of children living with serious illness. At the same time, such comprehensive physical, psychologic, social, and spiritual care benefits from an interdisciplinary approach.

The philosophy of palliative care can be successfully integrated into any hospital setting, including the ICU, when the focus of care also includes the prevention or amelioration of suffering and improving comfort and quality of life. All interventions that affect the child and family need to be assessed in relationship to these goals. This proactive approach asks the question, "What can we offer that will improve the quality of this child's life and provide the most meaning and sense of control and choice for their family?" instead of, "What therapies are we no longer going to offer this patient?" Staff may benefit from education, support, and guidance on the basic principles of pediatric palliative care, while using specialty-trained pediatric palliative care providers when available for additional support and expertise. *Regardless of the care setting, comprehensive palliative care requires an interdisciplinary approach that may include nurses, physicians, psychologists, psychiatrists, social workers, chaplains/clergy, child life specialists, and trained volunteers.*

GOALS OF CARE AND DECISION-MAKING

In the course of a child's serious illness, a series of important decisions may arise in relation to location of care, medications with risks and benefits, not starting or discontinuing life-prolonging treatments, experimental treatments in research protocols, and use of integrative therapies. Guided discussions around **goals of care** for the child provide opportunities to support decision-making. This is often accomplished

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Table 8.1 Conditions Appropriate for Pediatric Palliative Care

CONDITIONS FOR WHICH CURATIVE TREATMENT IS POSSIBLE BUT MAY NOT SUCCEED
Advanced or progressive cancer or cancer with a poor prognosis
Complex and severe congenital or acquired heart disease
CONDITIONS FOR WHICH THERE IS INTENSIVE LONG-TERM TREATMENT AIMED AT PROLONGING LIFE AND MAINTAINING QUALITY OF LIFE, BUT PREMATURE DEATH IS STILL POSSIBLE
Cystic fibrosis
Severe immunodeficiency
High-risk solid-organ transplant candidates and/or recipients (e.g., lung, multivisceral)
Chronic or severe respiratory failure
Muscular dystrophy
Complex multiple congenital malformation syndromes
Primary pulmonary hypertension
Severe chromosomal disorders (aneuploidy, deletions, duplications)
PROGRESSIVE CONDITIONS FOR WHICH THERE IS NO CURATIVE OPTION AND IN WHICH TREATMENT IS ALMOST EXCLUSIVELY PALLIATIVE AFTER DIAGNOSIS
Progressive metabolic disorders (Tay-Sachs disease)
Batten disease
Severe forms of osteogenesis imperfecta
CONDITIONS INVOLVING SEVERE, NONPROGRESSIVE DISABILITY, CAUSING EXTREME VULNERABILITY TO HEALTH COMPLICATIONS
Severe cerebral palsy with recurrent infection or difficult-to-control symptoms
Severe neurologic sequelae of infectious disease
Hypoxic or anoxic brain injury
Brain malformations (e.g., holoprosencephaly, lissencephaly)

Adapted from The Together for Short Lives (formerly the Association for Children's Palliative Care [ACT]) Life-limiting/Life-threatening Condition Categories. http://www.togetherforshortlives.org.uk/professionals/childrens_palliative_care_essentials/approach.

by eliciting parent (and child) understanding of the child's condition and asking open-ended questions that explore the parent's and child's hopes, worries, and family values. Goals-of-care conversations include what is most important for them as a family, considerations of their child's clinical condition, and their values and beliefs, including cultural, religious, and spiritual considerations (see Chapters 2 and 12). Table 8.2 presents specific questions that can effectively guide these discussions, and Figure 8.2 provides a basic framework illustrating a palliative-minded approach to care, anchored by eliciting goals of care and aligning care with those goals. The conversation should also include a review of previous discussions, active listening to concerns and issues as they are raised, opportunities to repeat back elements of the discussion to ensure clarity, and provision of honest, factual answers even in areas of uncertainty. As a provider, it is imperative to consider one's own views and implicit biases before entering into discussions with families who may identify with different cultures, races, or other social determinants (see Chapters 2, 3, and 12).

Decision-making should be focused on the goals of care, as opposed to limitations of care: "This is what we can offer," instead of, "There is nothing more we can do." Rather than meeting specifically to discuss discontinuing life-prolonging therapies or a do-not-resuscitate (DNR) order, a more general discussion centered on the goals of care will naturally lead to considering which interventions are in the child's best interests and can present an opportunity for the clinicians to make recommendations based on these goals. By offering medical recommendations based on family goals and the clinical reality, the team can decrease the burden of responsibility for decision-making that parents carry.

Conflicts in decision-making can occur within families, within healthcare teams, between the child and family, and between the family and care team (see Chapter 6). For children who are developmentally unable to provide guidance in decision-making (neonates, very young children, or children with severe cognitive impairment), parents and healthcare professionals may come to different conclusions as to what is in the child's best interests. Decision-making around the care of adolescents presents specific challenges, given the shifting boundary that separates childhood from adulthood. In some families and cultures, open disclosure and

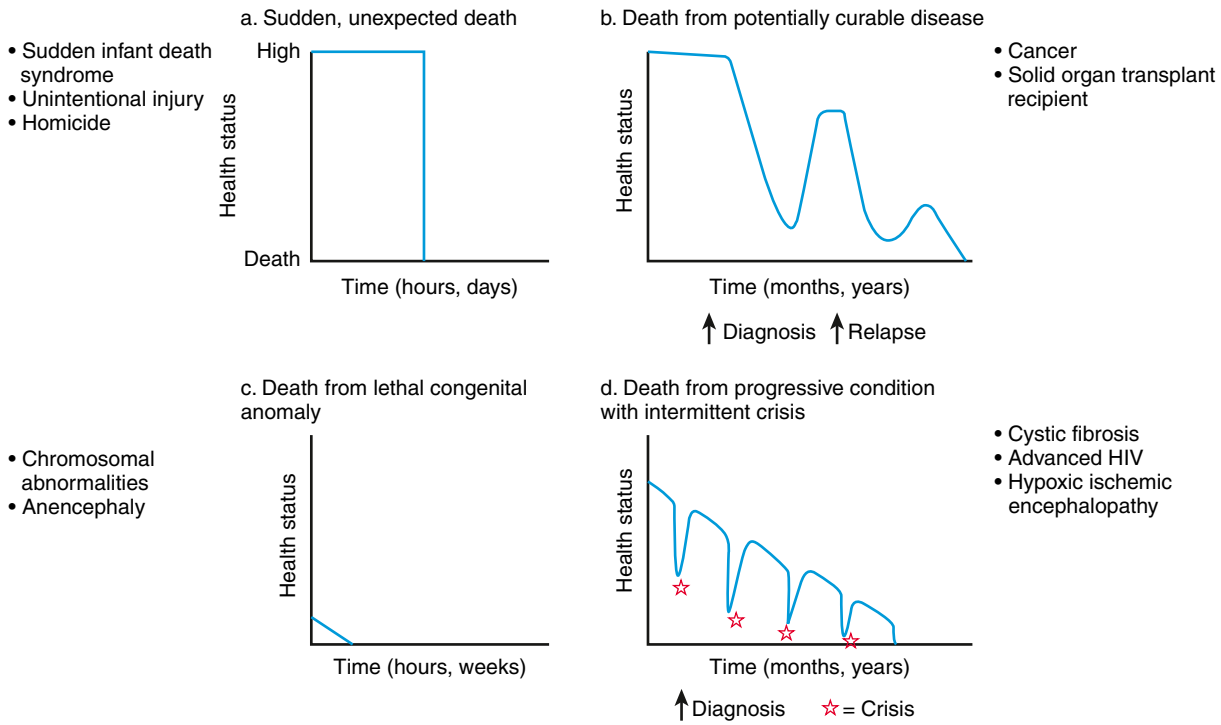

Fig. 8.1 Typical illness trajectories for children with life-threatening illness. (*From Field M, Behrman R [eds]. When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families. Washington, DC: National Academies Press;2003: 74.*)

autonomy are secondary to maintaining the integrity of the family (see Chapter 12). Although frequently encountered, differences in opinion are often manageable for all involved when lines of communication are kept open, team and family meetings are held, and the goals of care are clear.

ADVANCE CARE PLANNING

Although accurate prognostication is a particular challenge in pediatrics, the medical team often recognizes a poor prognosis before the prognosis is understood by parents or the child. This delay may impede informed decision-making about how the child lives at the end of life. Given the inherent prognostic uncertainty of a serious, life-threatening diagnosis, discussions concerning resuscitation, symptom control, and end-of-life care planning should be initiated when the physician recognizes that a significant possibility of patient mortality exists. Having these conversations in the midst of a crisis is not ideal. Whenever possible, they should occur well in advance of the crisis or when the patient has recovered from a crisis but is at high risk for others.

Patients and families are most comfortable being cared for by physicians and other care providers with whom they have an established relationship. Even in the face of long-standing and highly connected relationships, clinicians often hold assumptions about parent prognostic awareness, as well as parent readiness and willingness to have such discussions. In an attempt to protect families, clinicians may avoid conversations they perceive as promoting distress or hopelessness. However, parents greatly value honesty, and in fact such conversations can promote parent hopefulness and trust and connection with the care team. At times, a *consultative* specialty palliative care team provides the family with an opportunity to engage in sensitive conversations that may not as readily occur with the primary team, at least initially.

The population of individuals who die before reaching adulthood includes a disproportionate number of nonverbal and preverbal children and adolescents who are developmentally unable to make autonomous care decisions. Although parents are usually the primary decision-makers, these youth should be as fully involved in discussions and decisions about their care as appropriate for their developmental status. Using communication experts, child life therapists, chaplains, social workers, psychologists, and psychiatrists to allow children to express themselves through art, play, music, talk, and writing will enhance the provider's knowledge of the child's understanding and hopes. Tools such as **Five Wishes** (for adults), **Voicing My Choices** (for adolescents), and **My Wishes** (for school-age children) have in practice been useful in helping to introduce advance care planning to children, adolescents, and their families (www.agingwithdignity.org/index.php).

Table 8.2 Five Basic Questions to Guide the "Goals of Care" Conversation

PHRASING FOR ADULT OR OLDER ADOLESCENT	PHRASING FOR CHILD
Tell us about your child as a person. What does your child enjoy?	Tell me about yourself before you got sick.
What is your understanding of your child's illness/condition?	Why are you in the hospital? What do you understand about your illness?
In light of your understanding, what is most important to you regarding your child's care?	What do you want others to know or do for you when taking care of you?
What are you hoping for? What are your worries?	I wonder if there is anything that is worrying you or that is keeping you up at night. Is there anything you wish you could talk about?
What gives you strength in the face of your child's illness/condition?	What helps you get through the day? What helps you feel good?

Resuscitation Status

Many parents do not understand the legal mandate requiring attempted resuscitation for cardiorespiratory arrest unless a written DNR order is in place. In broaching this topic, rather than asking parents if they want to forgo cardiopulmonary resuscitation (CPR) for their child (and placing the burden of decision-making on them), discuss whether or not resuscitative interventions are likely to benefit the child. It is important to make recommendations based on overall goals of care and medical knowledge of potential benefit and/or harm of these interventions. Once the goals of therapy are agreed on, the physician is required to write a formal order. Out-of-hospital DNR verification forms are available which, if completed on behalf of the child, affirm that rather than initiating resuscitative efforts, emergency response teams are obligated to provide appropriate symptom management intended to support

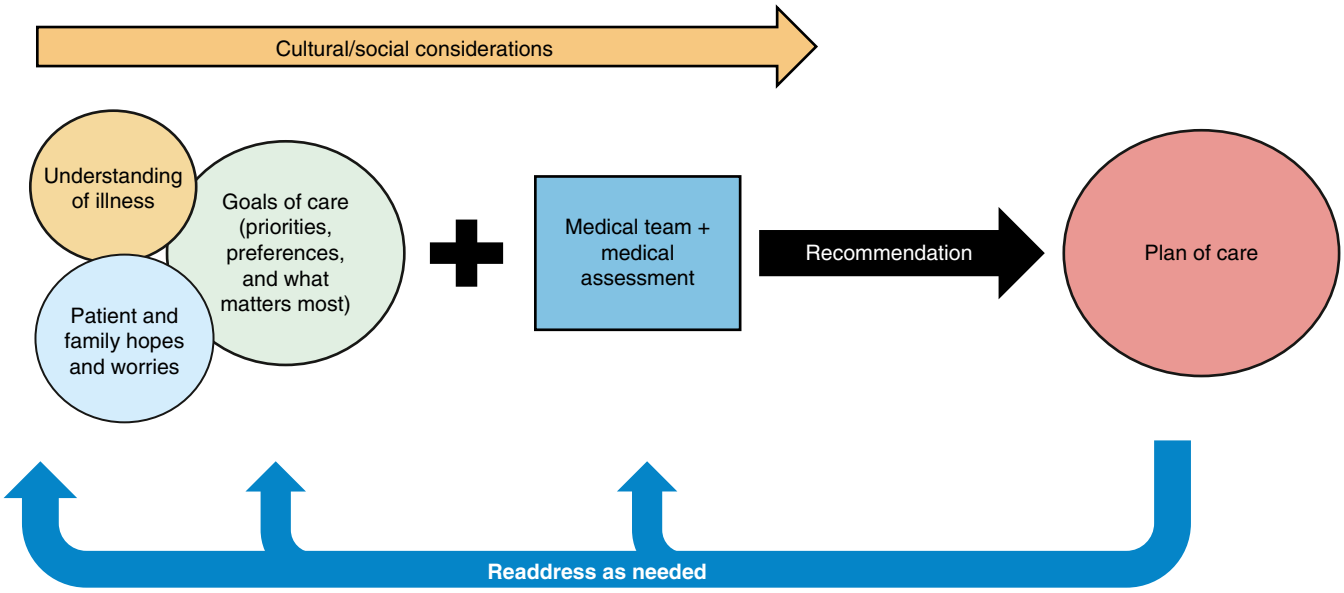

Fig. 8.2 A framework for creating plans of care with a palliative-minded approach, anchored by patient/family goals of care.

comfort and relief of suffering with appropriate interventions when called to the scene.

All states have implemented the **physician orders for life treatment (POLST) system**. A POLST order is completed for children with life-threatening illness, creating actionable orders for interventions to pursue versus avoid based on the expressed parent's and/or child's wishes (polst.org). It is usually helpful to frame discussions about POLST as ways for parents to maintain some control by communicating their goals and care preferences so their wishes may be honored, irrespective of the setting. It may also be beneficial to write a letter that delineates decisions regarding resuscitation interventions and supportive care measures to be undertaken for the child, particularly if POLST are not available. The letter should be as detailed as possible, including recommendations for comfort medications and contact information for the care team best known to the patient. Such a letter, given to the parents, with copies to the involved care team and institutions, can be a useful communication aid, especially in times of crisis. In any case, if a child dies in the home setting and the parents opt to use an out-of-hospital DNR verification form or POLST, plans to pronounce the child and provide support for the family must be in place. If the child has been referred to hospice, the hospice usually fulfills those responsibilities.

CARE SETTINGS

Pediatric palliative care should be provided across settings, including hospital, outpatient, and home, as well as pediatric nursing facilities and sometimes inpatient hospice locations. **Home care** for the child with a life-threatening illness requires 24 hour/day access to experts in pediatric palliative care, a team approach, and an identified coordinator who serves as a link among hospitals, the community, and specialists and who may assist in preventing or arranging for hospital admissions, respite care, and increased home care support as needed based on the child's clinical condition and goals of care. Adequate home care support and respite care, although sorely needed, is often not readily available, given gaps in staffing or the high-tech skills required to care for these children. Furthermore, families may view using respite care as a personal failure, or they may worry that others cannot adequately care for their child's special needs or potential rapid escalation of symptoms.

In the United States, the healthcare and reimbursement structure, combined with frequent use of medical technology (e.g., home ventilatory support) or continuous home nursing, historically precluded formal enrollment of children on the hospice benefit when they were otherwise eligible (i.e., had estimated prognosis of ≤6 months). Section 2302 of the Patient Protection and Affordable Care Act (ACA), the Concurrent Care for Children Requirement (CCCR), eliminated the requirement that Medicaid patients <21 years old forgo curative or life-prolonging therapies to be eligible for hospice. Although Medicaid programs in every state are required to provide concurrent curative/life-prolonging treatment and hospice services for hospice-eligible children, development of systems to make such concurrent care a reality has been slow. A limitation of the CCCR is that it does not expand access to hospice for children with life-threatening illness who do not meet hospice eligibility criteria (i.e., have a prognosis that cannot be estimated to be <6 months) or those not receiving Medicaid.

A number of state-based pediatric palliative care coalitions have formed to improve access to home-based pediatric hospice/palliative care services, using strategies such as Medicaid waivers or state plan amendments to increase coverage for hospice services. A growing number of home care agencies have also developed palliative care programs that serve as a bridge to hospice services for children not yet meeting hospice eligibility criteria. Some hospices have adopted an **open hospice** model with more flexible eligibility criteria. However, provision of hospice or palliative care for children is often also limited by the availability of clinicians who have training or experience in caring for seriously ill children. Furthermore, there are only a few inpatient facilities in existence within the United States that provide end-of-life care exclusively to pediatric patients.

At the end of life, children and families may need intensive support. About half of pediatric deaths occur in acute care hospitals, and end-of-life care may otherwise be provided in the home, pediatric nursing facility, or hospice house. Families need to feel safe and well cared for and given permission, if possible, to choose the location of care. In tertiary care hospitals, most children die in the neonatal and pediatric ICUs. In some instances, when death at home for a child in the ICU is preferred, transport and even extubation at home may be possible, if clinical and logistical circumstances permit it and support it.

COMMUNICATION AND ANTICIPATORY GUIDANCE

Parents

For parents (parents defined as any primary caregivers for children), **compassionate communication** with medical providers who understand their child's illness, treatment options, and family beliefs and goals is the cornerstone of caring for children with serious illness. During this time, one of the most significant relationships is that with the child's primary care clinician, who often has an enduring relationship with the child and family, including healthy siblings. Although a family's goals may change with the child's evolving clinical condition and other variable factors, *parents need to know that their child's primary care clinician will not abandon them as the goals of care evolve.* A flexible approach rooted in ongoing communication and guidance that incorporates understanding of the family's values, goals, and religious, cultural, spiritual, and personal beliefs is of paramount importance.

Pediatricians should recognize the important role they have in continuing to care for the child and family, because the primary goal of treatment may simultaneously be prolongation of life as well as comfort, relief of suffering, and promoting quality of life. Regular meetings between the care team and the family are essential to reassess and manage symptoms, explore the impact of illness on immediate family members, and provide anticipatory guidance. At these meetings, important issues with lifelong implications for parents and their child may be discussed. Such discussions should be planned with care, ensuring that adequate time for in-depth conversation is allotted; a private, physical setting is arranged; devices are silenced; and both parents and others who might be identified by the family as primary supports are present. Strategies for facilitating conversations related to goals of care and decision-making are detailed later.

Families may look to their pediatrician for assurance that all treatment options have been explored. Assisting a patient's family to arrange a second opinion may be helpful. Listening to families and children speak about the future even in the face of a poor prognosis may help keep the focus on living even while the child may be dying. Hoping for a miracle can coexist for parents even as they are facing and accepting the reality of death.

Parents also need to know about the availability of home care, respite services, web-based support (e.g., www.courageousparentsnetwork.org), educational materials, and support groups. Responding to parental requests or need for counseling referrals for themselves, other children, or the family is essential. Also, attending to the concrete needs of families (e.g., financial, insurance, housing) can be paramount in freeing them from worries that might interfere or compete with their ability to be fully present in their child's care.

When closer to the patient's end of life, although broaching the topic may seem daunting, exploration of how parents envision their child's death, addressing their previous loss experiences (most often with death of an adult relative) and any misconceptions, is often a great relief. *Learning about cultural, spiritual, and family values regarding pain management, suffering, and the preferred place of end-of-life care is essential* (see Chapters 2 and 12). Even mentioning funeral arrangements, possible autopsy, and organ/tissue donation pre-emptively can be helpful to give parents choices and know that these considerations can be discussed without fear. A major worry of many parents is how to involve and communicate with siblings, as well as the child, about the likelihood of impending death.

Ratings of "high satisfaction" with physician care have been directly correlated with receiving **clear communication** around end-of-life issues, delivered with sensitivity and caring; such communication included speaking directly to the child when appropriate. Communication may be complicated by **mutual protection** in which the child

wants to protect his or her parents, and likewise the parents want to protect their child, from painful information, sadness, or fear. Honoring the uniqueness of the child and understanding and respecting the family's communication style, values, spirituality, and culture are critical in these highly sensitive conversations. Evidence shows that parents who have open conversations with their child about death and dying do not regret having done so, whereas many parents who do not engage in these conversations regret avoiding them.

In communications with the child and family, the physician should avoid giving specific estimates of survival length, even when the child or family explicitly asks for them. These predictions are invariably inaccurate because population-based statistics do not predict the course for individual patients. A more honest approach may be to explore *ranges of time in general terms* (days to weeks, weeks to months, months to years) while recognizing that children with serious illness are also susceptible to acute events that cause rapid deterioration. The physician can also ask parents what they might do differently if they knew how long their child would live, then assist them in thinking through the options relating to their specific concerns (e.g., suggest celebrating upcoming holidays or important events earlier to take advantage of times when the child may be feeling better). It is generally wise to suggest that relatives who wish to visit might do so earlier rather than later, given the unpredictable trajectory of many conditions.

For the child and family, the integration of "bad news" is a *process,* not an event, and when done sensitively, does not take away hope or alter the relationship between the family and physician. The physician should expect that some issues previously discussed may not be fully resolved for the child and parents (e.g., DNR orders, artificial nutrition or hydration) and may need to be revisited over time. Parents of a child with a chronic illness may reject the reality of an impending death because past predictions may not have been accurate. Whether they are parents of a child with a chronic illness or a child whose death is the result of an accident or sudden catastrophic illness, they may experience great anxiety, guilt, or despair.

The Child

Truthful communication that takes into account the child's developmental stage and unique lived experience can help to address the fear and anxiety commonly experienced among children with serious illness. Responding in a developmentally appropriate fashion (Table 8.3) to a child's questions about death (e.g., "What's happening to me?" or "Am I dying?") requires a careful exploration of what is already known by the child, what is really being asked *(the question behind the question),* and why the question is being asked at this particular time and in this setting. It may signal a need to be with someone who is comfortable listening to such unanswerable questions. Many children find nonverbal expression much easier than talking; art, play therapy, and storytelling may be more helpful than direct conversation.

A child's perception of death depends on his or her conceptual understanding of *universality* (that all things inevitably die), *irreversibility* (that dead people cannot come back to life), *nonfunctionality* (that being dead means that all biologic functions cease), and *causality* (that there are objective causes of death).

Very young children may struggle with the concepts of irreversibility and nonfunctionality. For young school-age children, who are beginning to understand the finality of death, worries may include *magical thinking* in which their thoughts, wishes, or bad behavior might be the underlying cause for their illness. Older children seek more factual information to gain some control over the situation.

Children's fears of death are often centered on the concrete fear of being separated from parents and other loved ones and what will happen to their parents rather than themselves. This can be true for teens and young adults as well. This fear may be responded to in different ways: some families may give reassurance that loving relatives will be waiting, and others use religious concepts to refer to an eternal spiritual connection.

Adolescents may have a conceptual understanding of death similar to that of adults, but working with the adolescent with life-threatening illness presents unique concerns and issues. The developmental work of adolescence includes separating from their parents, developing strong peer relationships, and moving toward independent adulthood. For this population, the teenager's developmental need to separate is complicated by the increasing dependence both physically and emotionally on their parents. Providing space for these conversations and communicating openly and honestly supports independence while also meeting the adolescent's individual need.

In addition to developmental considerations, understanding related to the child's life experiences, the length of the child's illness, the understanding of the nature and prognosis of the illness, the child's role in the family, and the complex relationship between the child and their parents as primary caretakers should be considered in communication with children.

The question of whether and when to involve adolescents in decision-making arises particularly often. There is no one answer to this question. Instead, numerous considerations should be taken into account, including the adolescent's chronological age, developmental stage, adolescent preference with regard to such participation, and the family's preferred approach to communication and decision-making.

Parents have an instinctive and strong desire to protect their children from harm. When facing the death of their child, many parents attempt to keep the reality of impending death hidden from their child, hoping the child can be protected from the harsh reality. Although it is important to respect parental wishes, it is also true that most children already have a sense of what is happening to their bodies, even when it has been purposely left unspoken. Children may blame themselves for their illness and the resulting hardships for their loved ones. *Perpetuating the myth that "everything is going to be all right" takes away the chance to explore fears and provide reassurance.* Assisting parents to understand that the key to honest communication is not telling a child he or she is dying, but opening the door to conversation and validating what the child *already knows*. Honest communication also allows opportunities for memory and legacy making and saying goodbye.

School is the work of childhood and adolescence and is important in optimizing quality of life for a child seeking normalcy in the face of illness. Finding ways to help children and their families to maintain these connections through modification of the school day and exploring options to promote educational and social connections into the home or into the hospital room can be meaningful in the event that a child is not well enough to attend school. Video conferencing can be readily arranged from almost any setting.

The Siblings

Siblings are at special risk both during their sibling's illness and after the death. Because of the extraordinary demands placed on parents to meet the needs of their ill child, healthy siblings may feel their own needs are not being acknowledged or fulfilled. These feelings of neglect may then trigger guilt about their own good health and resentment toward their parents and ill sibling. Younger siblings may react to the stress by becoming seemingly oblivious to the turmoil around them. Some younger siblings may feel guilty for wishing the affected child would die so they could get their parents back (magical thinking). Parents need to know that these are normal responses, and siblings should be encouraged to maintain the typical routines of daily living. Siblings who are most involved with their sick sibling before death usually adjust better both at the time of and after the death. Acknowledging and validating sibling feelings, being honest and open, and appropriately involving them in the life of their sick sibling provide a good foundation for the grief process. It is often helpful to identify a person in the family (e.g., caring aunt) or school (e.g., counselor) to offer confidential and supportive opportunities for the sibling to reflect on their family experience, particularly as parents may be too overwhelmed to provide this at crucial times.

The Staff

Inadequate support for the staff providing palliative care can result in depression, emotional withdrawal, and other symptoms. Offering educational opportunities and emotional support in the form of both

Table 8.3 Developmental Questions, Thoughts, and Concepts of Dying, with Responsive Strategies

TYPICAL QUESTIONS AND STATEMENTS ABOUT DYING	THOUGHTS THAT GUIDE BEHAVIOR	DEVELOPMENTAL UNDERSTANDING OF DEATH	STRATEGIES AND RESPONSES
MONTHS TO 3 YR OF AGE			
"Mommy, don't cry." "Daddy, will you still tickle me when I'm dead?"	Child has limited understanding of events, future and past, and of the difference between living and nonliving.	Child may have "sense" that something is wrong. Death is often viewed as continuous with life (analogous to being awake and being asleep).	Optimize comfort and consistency; familiar persons, objects, routines. Use soothing songs, words, and touch. "I will always love you." "I will always take care of you." "I will tickle you forever."
AGE 3-5 YR			
"I did something bad and so I will die." "Can I eat anything I want in heaven?"	Concepts are simple and reversible. Variations between reality and fantasy.	Child may see death as temporary and reversible and not universal. Child may feel responsible for illness. Death may be perceived as an external force that can get you.	Assure child that illness is not their fault. Provide a consistent care team. Promote honest, simple language. Use books to explain the life cycle and promote questions and answers. "You did not do anything to cause this." "You are so special to us, and we will always love you." "We know (God, Jesus, Grandma, Grandpa) are waiting to see you."
AGE 5-10 YR			
"How will I die?" "Will it hurt?" "Is dying scary?"	Child begins to demonstrate organized, logical thought. Thinking becomes less esoteric. Child begins to problem-solve concretely, reason logically, and organize thoughts coherently. However, child has limited abstract reasoning.	Child begins to understand death as real and permanent. Death means that your heart stops, your blood does not circulate, and you do not breathe. It may be viewed as a violent event. Child may not accept death could happen to himself or herself or to anyone he or she knows, but starts to realize that people they know will die.	"Tell me why you are asking." Be honest and provide specific details if they are requested. Help and support the child's need for control. Permit and encourage the child's participation in decision-making. "We will work together to help you feel comfortable. It is very important that you let us know how you are feeling and what you need. We will always be with you, so you do not need to be afraid."
AGE 10-18 YR			
"I'm afraid if I die my mom will just break down." "I'm too young to die. I want to get married and have children." "Why is God letting this happen?"	Abstract thoughts and logic possible. Body image is important. Child needs peer relationships for support and for validation. Child expresses altruistic values, such as staying alive for family (parents, siblings) and donating organs/tissue. Disbelief that they are dying.	Understand death as irreversible, inevitable, and universal. Child needs reassurance of continued care and love. Search for meaning and purpose of life.	Reinforce child's/adolescent's self-esteem, sense of worth, and self-respect. Allow need for privacy, independence, access to friends and peers. Tolerate expression of strong emotions and permit participation in decision-making. "I can't imagine how you must be feeling. Despite it all, you are doing an incredible job. I wonder how I can help?" "What's most important to you now?" "What are your hopes … your worries?" "You have taught me so much; I will always remember you."

Adapted from Hurwitz C, Duncan J, Wolfe J. Caring for the child with cancer at the close of life, *JAMA*. 2003;292:2141–2149.

informal opportunities to express emotions or formal debriefs/check-ins for staff at various stages of caring for a child with life-threatening illness can be helpful in bettering patient/family care and preventing staff from experiencing compassion fatigue, burnout, and long-term repercussions, including leaving the field.

The Pediatric Clinician

Although optimal palliative care for children entails an interdisciplinary care team approach, pediatric clinicians are well positioned to support children and their families, particularly when they have a long-standing relationship with multiple family members. A primary care clinician who has cared for a family over time may already know and care for other family members, understand pre-existing stressors for the family, and be familiar with coping strategies used by family members. For this reason, trusted primary care clinicians may be best suited to explore goals of care, provide difficult news in a compassionate manner, and support families throughout the trajectory of illness. Specialty training is not needed to provide expert primary palliative care; rather, a motivation to guide decisions based on family goals and values and understanding of the community supports available are a sufficient starting point. Pediatric clinicians are familiar with the process of eliciting concerns and providing anticipatory guidance for parents, as well as developmentally appropriate explanations for children. Those interested in developing skillful communication techniques surrounding serious illness have many resources available, including VitalTalk (vitaltalk.org).

Symptom Management

Intensive symptom management is another cornerstone of pediatric palliative care. Alleviation of symptoms reduces suffering of the child and family and allows them to focus on other concerns and participate in meaningful experiences. Despite increasing attention to symptoms and pharmacologic and technical advances in medicine, children often suffer from multiple symptoms. Figure 8.3 provides key elements and general approaches to managing symptoms.

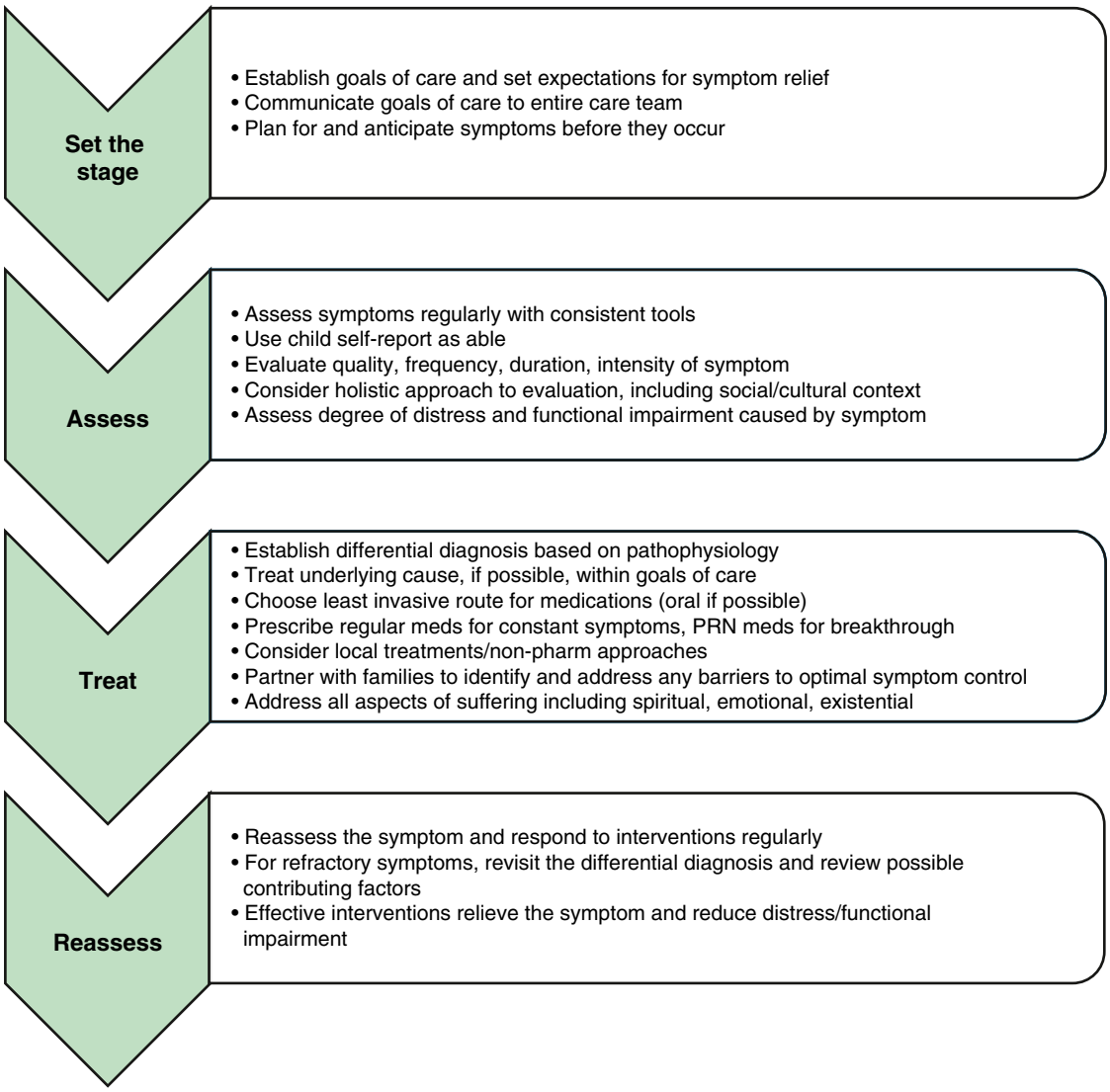

Fig. 8.3 Key elements of effective symptom management.

Pain is a complex sensation triggered by actual or potential tissue damage and influenced by cognitive, behavioral, emotional, social, and cultural factors. Effective pain relief is essential to prevent *central sensitization,* a central hyperexcitation response that may lead to hypersensitivity and escalating pain, and to diminish a stress response that may have a variety of physiologic effects. Assessment tools include self-report tools for children who can communicate their pain verbally and tools based on behavioral cues for children who are unable to do so because of their age, medical condition, or a neurodevelopmental disorder. Figure 8.4 and Tables 8.4 and 8.5 address management of pain (see also Chapter 93).

Many children with life-threatening illness experience pain that requires **opioids** for adequate relief at some point in their illness trajectory. The WHO pain guidelines recommend the first step for mild pain and the second step for moderate to severe pain (Fig. 8.4). Prescribing *codeine* should be avoided because of its side effect profile and lack of superiority over nonopioid analgesics. Furthermore, relatively common genetic polymorphisms in the *CYP2D6* gene lead to wide variation in codeine metabolism. Specifically, 10–40% of individuals carry polymorphisms causing them to be *poor metabolizers* who cannot convert codeine to its active form, *morphine,* and therefore are at risk for inadequate pain control. Others are *ultrametabolizers* who may even experience respiratory depression from rapid generation of morphine from codeine. It is therefore preferable to use a known amount of the active agent, morphine. Federal and state health agencies in the United States have put forth considerable effort in establishing guidelines for opioid prescribing. Before prescribing opioids, create an opioid agreement with patients and families, check the state's electronic prescription monitoring program, and limit opioid prescription for minors to 7 days or less for *initial* opioid prescription.

It is important to explore with families and members of the care team misconceptions that they may have regarding opioids, such as respiratory depression, addiction, dependence, the symbolic meaning of starting an opioid such as methadone or morphine and/or a morphine drip, and the potential for opioids to hasten death. *There is no association between administration or escalation of opioids and length of survival.* In fact, evidence supports longer survival in individuals with symptoms that are well controlled. Collaboration with specialty palliative care and/or hospice care teams can help guide complex symptom management.

Children with serious illness and medical complexity often experience a multitude of nonpain symptoms. A combination of both pharmacologic (see Table 8.4) and nonpharmacologic (see Table 8.5) interventions is often optimal. **Fatigue** is one of the most common symptoms in children with advanced illness. Children

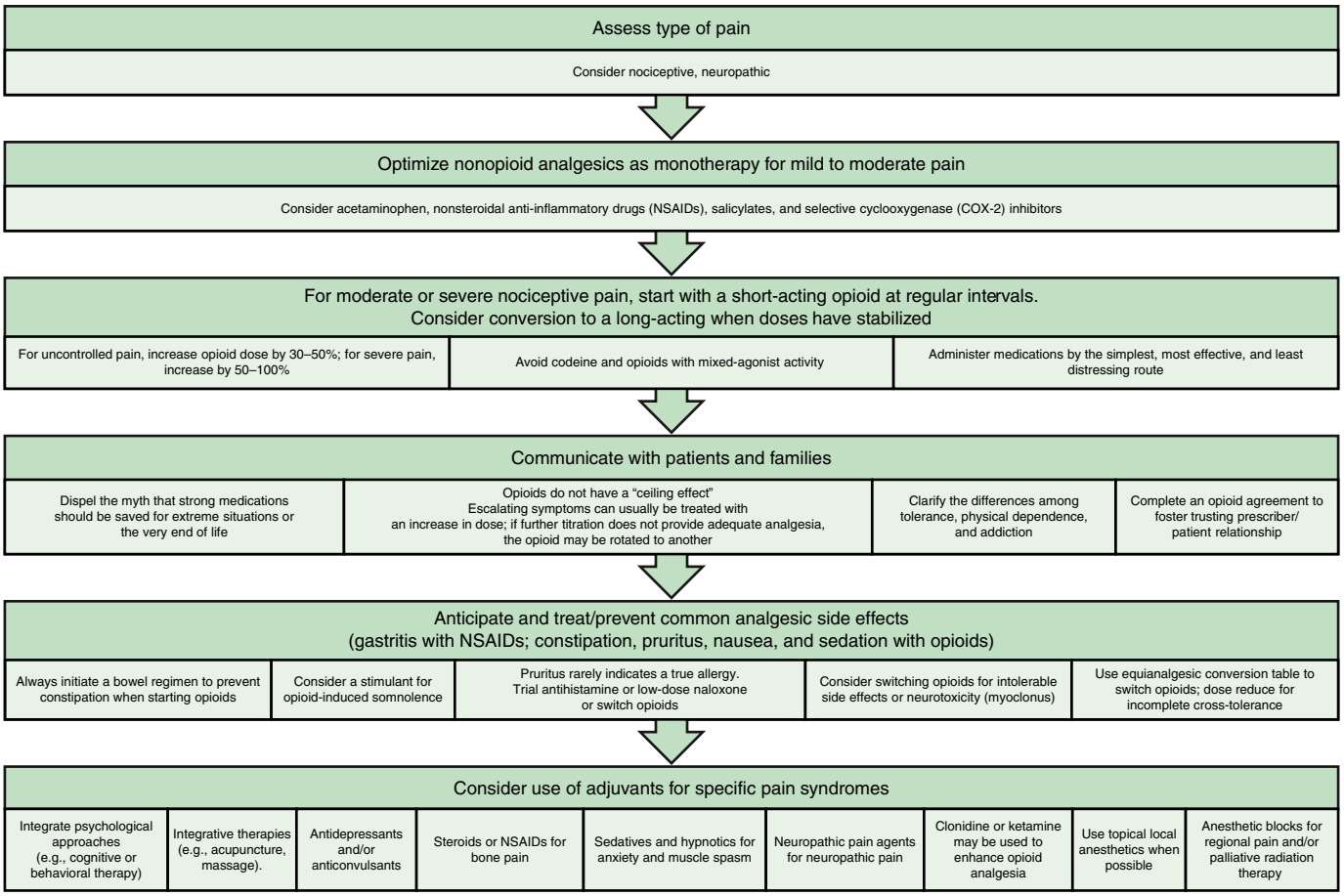

Fig. 8.4 Guidelines for pain management related to life-threatening illness.

Table 8.4 Pharmacologic Approach to Symptoms Commonly Experienced by Children with Life-Threatening Illness

SYMPTOM	MEDICATION	STARTING DOSE	COMMENTS
Pain—mild	Acetaminophen	15 mg/kg PO q4h, max 3 g/day or 40 mg/kg/day	Available PO (including liquid), PR, or IV
	Ibuprofen	10 mg/kg PO q6h	PO (including liquid) only; avoid if risk of bleeding; use only in infants ≥6 mo. Use with caution in congestive heart failure. Chewable tablets contain phenylalanine.
	Naproxen	5mg/kg PO q12h	Avoid if risk of bleeding; may cause nephrotoxicity.
	Celecoxib	1-2 mg/kg (max 100-200 mg) PO q12-24h	Selective cyclooxygenase (COX-2) inhibitor has low risk of gastritis and low antiplatelet activity.
	Ketorolac	0.5 mg/kg (15-30 mg) IV q6h, max 24h dose 120 mg	Do not use longer than 5 days; may cause nephrotoxicity.
Pain—moderate/severe	Morphine immediate release (i.e., MSIR)	0.3 mg/kg PO q4h if <50 kg 15 mg PO q4h if >50 kg*† 0.05-0.1 mg/kg IV q2-4h	Also available in IV/SC formulation. Reduce dose in renal/hepatic impairment.‡§
	Oxycodone	0.1 mg/kg PO q4h if <50 kg 5-10 mg PO q4h if >50 kg*†	No injectable formulation. Longer half-life than morphine. Reduce dose in renal/hepatic impairment.‡§
	Hydromorphone	0.05 mg/kg PO q4h if <50 kg 2-4 mg PO q4h if >50 kg*† 0.015 mg/kg IV q2-4h	Also available in IV/SC formulation. Injectable form very concentrated, facilitating subcutaneous delivery. Preferred drug in liver impairment.‡§
	Fentanyl	0.5-1.5 µg/kg IV/SC q30min*†	Rapid infusion may cause chest wall rigidity. Preferred drug in renal impairment.‡§

Continued

Table 8.4 Pharmacologic Approach to Symptoms Commonly Experienced by Children with Life-Threatening Illness—cont'd

SYMPTOM	MEDICATION	STARTING DOSE	COMMENTS
Pain—sustained-release formulations	MS Contin Kadian (contains sustained-release pellets) Oramorph	Total daily dose of MSIR divided bid-tid	Do not crush MS Contin. For those unable to swallow pills, Kadian capsules may be opened and contents mixed with food, but *cannot be chewed*. Kadian contents may be mixed in 10 mL water and given via 16-French G-tube. Larger-dose formulation may not be suitable for small children.§
	Oxycontin	Total daily dose of oxycodone divided bid-tid	Do not crush.§
	Transdermal fentanyl patch	Divide total 24 hr PO morphine dose by 2 to determine starting dose of transdermal fentanyl. No data exist on the equianalgesic conversion from transdermal fentanyl to any oral opioid.	Smallest patch size may be too high for small children. Patches are for children >2 yr. Apply to upper back in young children. Patch may **not** be cut. Typically for patients taking at least 60 mg morphine/day or its equivalent. Not appropriate when dosage changes are frequent or for opioid-naïve patients. Fever >40°C results in higher serum concentrations.§
	Methadone	Starting dose 0.1-0.2 mg/kg PO bid. May give tid if needed. Recommend consultation with experienced clinician for equivalence dosing from other opioids.*†	Only opioid with immediate and prolonged effect; available as a liquid; do not adjust dose more often than every 72 hr because prolonged biologic half-life is greater than therapeutic half-life. Knowledge of methadone pharmacokinetics is needed for converting to and from doses of other opioids. Also available IV/SC. May cause QT interval prolongation (consider ECG), especially in adults on >200 mg/day or in those at risk for QT prolongation. Interacts with several antiretroviral, antiepileptic agents.§
Pain—Neuropathic	Gabapentin	Start at 5 mg/kg/day at bedtime and gradually increase to 10-15 mg/kg/day divided tid; titrate up by 5 mg/kg/day q3-4 days as needed, but not to exceed 50-75 mg/kg/day (3,600 mg/day)	May cause neuropsychiatric events in children (aggression, emotional lability, hyperkinesia), usually mild but may require discontinuation of gabapentin. May cause dizziness, drowsiness, tremor, nystagmus, ataxia, and swelling.
	Nortriptyline	0.5 mg/kg PO at bedtime (max 150 mg/day). Begin at lower dose and titrate every 3-4 days until therapeutic effect or max dose.	Fewer anticholinergic side effects than amitriptyline. May cause constipation, sedation, postural hypotension, and dry mouth. May cause QT interval prolongation (consider ECG). At higher doses, monitor ECG and plasma levels.
	Pregabalin	Start at 1 mg/kg/dose PO at bedtime for 3 days, then increase to 1 mg/kg/dose bid. Increase every 3 days to 3 mg/kg/dose PO bid (max 6 mg/kg/dose).	See gabapentin.
	Methadone	See previous listing	See previous listing.
Dyspnea	Morphine, immediate release (i.e., MSIR)	0.1 mg/kg PO q4h prn*†	All opioids may relieve dyspnea. For dyspnea, the starting dose is 25–35% of the dose that would be administered for pain.§
	Lorazepam	0.025-0.05 mg/kg IV/PO q6h, up to 2 mg/dose	See previous listing For anxiety contributing to dyspnea
Respiratory secretions	Scopolamine patch	1.5 mg patch, change q72h (for children >8-12 yr old)	Excessive drying of secretions can cause mucus plugging of airways. Good for motion-induced nausea and vomiting. Handling patch and contacting eye may cause anisocoria and blurry vision. May fold patches, but do not cut them. Anticholinergic side effects possible.
	Glycopyrrolate	0.04-0.1 mg/kg PO q4-8h	Powerful antisialagogue. Excessive drying of secretions can cause mucus plugging of airways. Anticholinergic side effects possible. Quaternary ammonium structure limits its ability to cross lipid membranes, such as the blood-brain barrier (in contrast to atropine, scopolamine, and hyoscyamine sulfate), so may exert fewer central anticholinergic effects.
	Hyoscyamine sulfate	PO/SL: *2-12 yr*: 0.0625-0.125 mg q4h as needed; max daily dosage 0.75 mg *or* timed release 0.375 mg q12h; max daily dosage 0.75 mg *>12 yr-adult*: 0.125-0.25 mg q4h as needed; max daily dosage 1.5 mg *or* timed release 0.375-0.75 mg q12h; max daily dosage 1.5 mg	Anticholinergic side effects possible, including sedation. May be given sublingually.
	Atropine	1-2 gtt SL q4-6h prn	Give 0.5% ophthalmic drops sublingually.

Table 8.4 Pharmacologic Approach to Symptoms Commonly Experienced by Children with Life-Threatening Illness—cont'd

SYMPTOM	MEDICATION	STARTING DOSE	COMMENTS
Nausea	Metoclopramide	0.1-0.2 mg/kg/dose q6h, up to 10 mg/dose (prokinetic and mild nausea dosing). For chemotherapy-associated nausea, 0.5-1 mg/kg q6h prn PO/IV/SC; give with diphenhydramine and continue diphenhydramine for 24 hr after last dose of high-dose metoclopramide to prevent extrapyramidal reaction.	Helpful when dysmotility is an issue; may cause extrapyramidal reactions, particularly in children after IV administration of high doses. Contraindicated in complete bowel obstruction or pheochromocytoma. Avoid concomitant use with olanzapine.
	Ondansetron	0.15 mg/kg dose IV/PO q8h prn. No single IV dose should exceed 16 mg because of risk of QT prolongation.	Significant experience in pediatrics. Good empirical therapy for nausea in palliative care population. Oral dissolving tablet contains phenylalanine. Higher doses used with chemotherapy, although single 32 mg IV dose is no longer available (risk for QT prolongation). Consider ECG monitoring in patients with electrolyte abnormalities, congestive heart failure, bradyarrhythmias, or in patients taking other medications with the potential to cause QT prolongation. May cause constipation.
	Dexamethasone	0.1 mg/kg/dose tid PO/IV; max dose 10 mg/day	Also helpful with hepatic capsular distension, bowel wall edema, anorexia, increased ICP. May cause mood swings or psychosis.
	Lorazepam	See previous listing.	Helpful for anticipatory nausea
	Dronabinol	<6 *yr*: No dosing information; use with caution 6-12 *yr*: 2.5-5 mg/dose PO q6h prn or scheduled >*12 years:* 5-7.5 mg/dose PO q6h prn or scheduled; max dosage (escalating): 5 mg 4 times/day (20 mg/day)	Available in 2.5 and 5 mg capsules and 5 mg/mL liquid. May remove liquid contents from capsules for children who cannot swallow capsules. Avoid in patients with sesame oil hypersensitivity or history of schizophrenia. May cause euphoria, dysphoria, strange dreams, or other mood changes. Tolerance to CNS side effects usually develops in 1-3 days of continuous use. Avoid in patients with depression or mania.
	Scopolamine patch	See previous listing	See previous listing
	Olanzapine	4-6 yr: 1.25 mg PO daily 6-12 yr: 2.5 mg PO daily ≥12 yr: 5 mg daily; doses may be titrated to max of 10 mg/day	Little evidence to guide antiemetic dosing. Ranges largely derived from olanzapine dosing for other purposes. Avoid concomitant use with metoclopramide.
Anxiety	Lorazepam	See previous listing	See previous listing
Agitation/ delirium	Haloperidol	0.01 mg/kg PO tid prn for acute onset: 0.025-0.050 mg/kg PO, may repeat 0.025 mg/kg in 1 hr prn	May cause extrapyramidal reactions, which can be reversed with diphenhydramine or Cogentin. Safety not established in children <3 yr.
Sleep disturbance/ insomnia	Trazodone	Children 6-18 yr: 0.75-1 mg/kg/dose, given bid-tid if needed If >18 yr, start at 25-50 mg/dose, given bid-tid if needed Max dose 150 mg/dose	Potentially arrhythmogenic
Fatigue	Methylphenidate	0.3 mg/kg/dose (2.5-5 mg) titrated as needed, up to 60 mg/day	Rapid antidepressant effect; also improves cognition. Administer before meals to avoid appetite suppression. Use with caution in children at risk for cardiac arrhythmia. Available as liquid and chewable tablet and transdermal patch.
Pruritus	Diphenhydramine	0.5-1 mg/kg q6h IV/PO (100 mg max per day)	Indicated for histamine-mediated itch. May reverse phenothiazine-induced dystonic reactions. Topical formulation on large areas of the skin or open area may cause toxic reactions. May cause paradoxical reaction in young children. Typically ineffective for opioid-associated pruritus.
	Hydroxyzine	0.5-1 mg/kg q6h IV/PO (600 mg max per day)	
	Naloxone	0.25-2 mcg/kg/hr continuous IV infusion	Low-dose continuous infusion indicated for opioid-induced itch
	Nalbuphine	0.02 mg/kg (1.5 mg) IV q6h PRN	For opioid-induced itch
Constipation	Docusate	40-150 mg/day PO in 1-4 divided doses	Stool softener available as liquid or capsule

Continued

Table 8.4 Pharmacologic Approach to Symptoms Commonly Experienced by Children with Life-Threatening Illness—cont'd

SYMPTOM	MEDICATION	STARTING DOSE	COMMENTS
	MiraLAX	<10 kg: ¼ scoop (4.25 g) daily <5 yr: 1/2 scoop (8.5 g) in 4 oz water daily *>5 yr*: 1 scoop (17 g) in 8 oz water daily	Tasteless powder may be mixed in beverage of choice. Now available over the counter.
	Lactulose	5-10 mL PO up to q2h until bowel movement or 15-30 mL PO bid	Bowel stimulant; dosing q2h may cause cramping.
	Senna	2.5-5 mL PO daily (for children >27 kg)	Bowel stimulant; available as granules
	Dulcolax (bisacodyl)	3-12 yr: 5-10 mg PO daily >12 yr 5-15 mg PO daily	Available in oral or rectal formulation
	Pediatric Fleets Enema	*2-4 yr*: Administer one half contents of one 2.25 oz pediatric enema *5-11 yr*: Administer contents of one 2.25 oz pediatric enema ≥*12 yr* and adolescents: Administer contents of one 4.5 oz enema as single dose	May repeat ×1 if needed. Do not use in neutropenic patients.
	Methylnaltrexone	10 mg/dose 10-20 kg: 2 mg SC 21-33 kg: 4 mg SC 34-46 kg: 6 mg SC 47-62 kg: 8 mg SC 63-114 kg: 12 mg SC ≥115 kg: 0.15 mg/kg SC Administer 1 dose every other day as needed; max 1 dose/24 hr	Peripherally acting opioid antagonist for opioid-induced constipation. Usually works within 30-60 min of administration. May cause cramping.
Muscle spasm	Diazepam	Oral/IM/IV: *<50 kg*: 0.05 mg/kg q6h (titrate to 0.2 mg/kg/dose max) *>50 kg*: 2.5 mg q6h (titrate to 10 mg/dose max)	May be irritating if given by peripheral IV line.
	Baclofen	5 mg PO tid, increase by 5 mg/dose as needed. Max 80 mg/day.	Helpful with neuropathic pain and spasticity; abrupt withdrawal may result in hallucinations and seizures; not for children <10 yr
Seizures	Lorazepam	0.1 mg/kg IV/PO/SL/PR repeat q10min × 2	
	Diazepam	0.1 mg/kg IV/PO q6h (max 5 mg/dose if <5 yr; max 10 mg/dose if >5 yr)	May be given PR as Diastat (0.2 mg/kg/dose q15min ×3 doses)
Neuroirritability	Gabapentin	See previous listing	
	Clonidine	Oral or transdermal patch: Initial dosing: 5 mcg/kg/day; divide daily dose into q8-12h for enteral dosing, or round daily dose to nearest ¼ patch size for transdermal dosing (max initial dose 100 mcg/day) Increase gradually if needed by 2.5 mcg/kg/day; max dose 25 mcg/kg/day (up to max 0.6 mg/day). May switch from oral to transdermal route once optimal oral dose is established. Transdermal dose is equivalent to the total oral daily dose (e.g., if total oral dose is 0.1 mg/day, apply 1 patch [delivers 0.1 mg/day]). Change patch every 7 days.	Transdermal patch may contain metal (e.g., aluminum) that may cause burns if worn during MRI scan. Remove patch before MRI. Patch may be cut into 1/4 or 1/2 fractions based on dose needed.
	Clonazepam	<10 yr or <30 kg: initial dose 0.01-0.03 mg/kg/day divided tid ≥10 yr (≥30 kg): initial dose up to 0.25 mg PO tid; may increase by 0.5-1 mg/day every 3 days Maintenance dose: 0.05-0.2 mg/kg/day up to 20 mg/day	
Appetite stimulation	Dronabinol	See previous listing	See previous listing
	Cyproheptadine	Children ≥2 yr and adolescents: 0.08 mg/kg PO q8h; if no benefit in 5 days, increase dose by 0.04-0.08 mg/kg/dose Max daily dose: ≤6 yr: 12 mg/day; 7-14 yr: 16 mg/day; ≥15 yr: 32 mg/day	Potent antihistamine and serotonin antagonist

*Infants <6 mo should receive 25–30% of the usual opioid starting dose.
†Although the usual opioid starting dose is presented, the dose may be titrated as needed. There is no ceiling/maximum dose for opioids.
‡Breakthrough dose is 10% of 24 hr dose. See Chapter 76 for information regarding titration of opioids.
§Side effects from opioids include constipation, respiratory depression, pruritus, nausea, urinary retention, and physical dependence.
Note: Some medications or dosing may not apply to infants (≤12 mo). Verify suitability and dosing of all medications before administering to neonates.
IV, Intravenous(ly); PO, by mouth; PR, rectally; prn, as needed; gtt, drops; SC, subcutaneously; bid, twice daily; tid, 3 times daily; *q4h*, every 4 hours; q30min, every 30 minutes; CNS, central nervous system; ECG, electrocardiogram; ICP, intracranial pressure.
Adapted from Ullrich C, Wolfe J. Pediatric pain and symptom control. In Walsh TD, Caraceni AT, Fainsinger R, et al (eds): *Palliative Medicine*. Philadelphia: Saunders, 2008.

Table 8.5 Nonpharmacologic Approach to Symptoms Commonly Experienced by Children with Life-Threatening Illness

SYMPTOM	APPROACH TO MANAGEMENT
Pain	Prevent pain when possible by limiting unnecessary painful procedures, providing sedation, and giving preemptive analgesia before a procedure (e.g., including sucrose for procedures in neonates). Address coincident depression, anxiety, sense of fear, or lack of control. Consider guided imagery, relaxation, hypnosis, art/pet/play therapy, acupuncture/acupressure, cognitive behavioral therapy (CBT), physical therapy, biofeedback, massage, heat/cold, yoga, transcutaneous electric nerve stimulation, and distraction.
Dyspnea or air hunger	Wipe and/or suction oral secretions if present; positioning; comfortable loose clothing; fan to provide cool, blowing air. Limit volume of intravenous fluids; consider diuretics if fluid overload/pulmonary edema present. Behavioral strategies, including breathing exercises, guided imagery, relaxation, music, and distraction.
Fatigue	Sleep hygiene (establish a routine, promote habits for restorative sleep). Regular, gentle exercise; prioritize or modify activities. Address potentially contributing factors (e.g., anemia, depression, side effects of medications). Aromatherapy*: peppermint, rosemary, basil.
Nausea/vomiting	Consider dietary modifications (bland, soft, adjust timing/volume of foods or feeds). Aromatherapy*: ginger, peppermint, lavender, acupuncture/acupressure.
Constipation	Increase fiber in diet, encourage fluids, ambulation (if possible).
Oral lesions/ dysphagia	Oral hygiene and appropriate liquid, solid, and oral medication formulation (texture, taste, fluidity). Treat infections, complications (mucositis, pharyngitis, dental abscess, esophagitis).
	Oropharyngeal motility study and speech (feeding team) consultation.
Anorexia/cachexia	Manage treatable lesions causing oral pain, dysphagia, or anorexia. Support caloric intake during phase of illness when anorexia is reversible. Acknowledge that anorexia/cachexia is intrinsic to the dying process and may not be reversible. Prevent/treat coexisting constipation.
Pruritus	Moisturize skin. Trim child's nails to prevent excoriation. Try specialized anti-itch lotions. Apply cold packs. Counterstimulation, distraction, relaxation.
Diarrhea	Evaluate/treat if obstipation. Assess and treat infection. Dietary modification.
Depression	Psychotherapy, behavioral techniques, setting attainable daily goals. Aromatherapy*: bergamot, lavender.
Anxiety	Psychotherapy (individual and family), behavioral techniques. Aromatherapy*: clary sage, angelica, mandarin, lavender.
Agitation/terminal restlessness	Evaluate for organic or drug causes. Educate family. Orient and reassure child; provide calm, nonstimulating environment; use familiar music, verse, voice, touch. Aromatherapy*: frankincense, ylang.

*Best if aromatherapy is administered by a practitioner trained in aromatherapy use and safety and if child has choice of essential oil aroma that stimulates positive response.
From Sourkes B, Frankel L, Brown M, et al. Food, toys, and love: Pediatric palliative care. *Curr Probl Pediatr Adolesc Health Care*. 2005;35:345–392.

may experience fatigue as a physical symptom (e.g., weakness or somnolence), a decline in cognition (e.g., diminished attention or concentration), and impaired emotional function (e.g., depressed mood or decreased motivation). Because of its multidimensional and incapacitating nature, fatigue can prevent children from participating in meaningful or pleasurable activities, thereby impairing quality of life. Fatigue is usually multifactorial in etiology. A careful history may reveal contributing physical factors (uncontrolled symptoms, medication side effects), psychologic factors (anxiety, depression), spiritual distress, or sleep disturbance. It is important to explore a patient's sleep history and encourage behavioral interventions such as optimizing sleep hygiene (e.g., instituting a regular bedtime routine, limiting screens and physical activity before bed), and sticking to regular sleep and wake times as much as feasible. If biobehavioral approaches remain ineffective, pharmacologic approaches such as trazodone may be considered. Interventions to reduce fatigue include treatment of contributing factors, exercise, behavior modification strategies, and pharmacologic agents. Challenges to effectively addressing fatigue include the common belief that fatigue is inevitable, lack of communication between families and care teams about it, and limited awareness of potential interventions for fatigue.

Dyspnea (the *subjective* sensation of shortness of breath) results from a mismatch between afferent sensory input to the brain and the outgoing motor signal from the brain. It may stem from respiratory causes (e.g., airway secretions, obstruction, infection) or other factors (e.g., cardiac) and may also be influenced by psychologic factors (e.g., anxiety). Respiratory parameters such as respiratory rate and oxygen saturation correlate unreliably with the degree of dyspnea. Therefore giving oxygen to a cyanotic or hypoxic child who is otherwise quiet and relaxed may relieve staff discomfort while having no impact on patient distress and may also add burden if the child cannot tolerate the mask or cannula. *Dyspnea can be relieved with the use of regularly scheduled plus as-needed doses of*

opioids. Opioids work *directly* on the brainstem to reduce the sensation of respiratory distress, as opposed to relieving dyspnea by sedation. The dose of opioid needed to reduce dyspnea is as little as 25% of the amount that would be given for analgesia. Nonpharmacologic interventions, including guided imagery or hypnosis to reduce anxiety, or cool, flowing air, aimed toward the face, are also frequently helpful in alleviating dyspnea. Although oxygen may relieve hypoxemia-related headaches, it is no more effective than blowing room air in reducing the distressing sensation of shortness of breath.

As death approaches, a buildup of secretions may result in noisy respiration sometimes referred to with the outdated term "death rattle." Patients at this stage are usually unconscious, and noisy respirations are often more distressing for others than for the child. It is often helpful to discuss this anticipated phenomenon with families in advance, and if it occurs, to point out the child's lack of distress from it. Nonpharmacologic interventions include positional changes, and if treatment is needed, an anticholinergic medication, such as glycopyrrolate, may reduce secretions.

Neurologic symptoms include **seizures** that are often part of the antecedent illness but may increase in frequency and severity toward the end of life. A plan for managing seizures should be made in advance, and anticonvulsants should be readily available in the event of seizure. Parents can be taught to use rectal diazepam at home. Increased **neuroirritability** accompanies some neurodegenerative disorders; it may be particularly disruptive because of the resultant break in normal sleep–wake patterns and the difficulty in finding respite facilities for children who have prolonged crying or difficulty consoling. Such neuroirritability may respond to gabapentin. Judicious use of sedatives, benzodiazepines, clonidine, nortriptyline, or methadone may also reduce irritability without inducing excessive sedation; such treatment can dramatically improve the quality of life for both child and caregivers. **Increased intracranial pressure** and **spinal cord compression** are most often encountered in children with brain tumors or metastatic and solid tumors. Depending on the clinical situation and the goals of care, radiation therapy, surgical interventions, and steroids are potential therapeutic options.

Delirium is an underrecognized brain disorder characterized by waxing and waning attention, confusion, and disorientation. Agitation may occur along with features of hypomania. Although delirium as a whole is often not diagnosed, the hypomanic form is particularly underrecognized. Delirium has a range of causes, including electrolyte imbalances, organ dysfunction, sleep–wake cycle disturbances, and results of medications such as anticholinergics and benzodiazepines. Environmental strategies to calm and orient the child while addressing potentially contributing factors are helpful. In some patients, antipsychotic/neuroleptic medications are indicated (see Chapters 33 and 47).

Feeding and hydration issues can raise ethical questions that evoke intense emotions in families and medical caregivers alike. Options that may be considered to artificially support nutrition and hydration in a child who can no longer feed by mouth include nasogastric and gastrostomy feedings or intravenous nutrition or hydration (see Chapter 60). These complex decisions require evaluating the risks and benefits of artificial feedings and taking into consideration the child's functional level and prognosis. At times, it may be appropriate to initiate a trial of tube feedings, with the understanding that they may be discontinued at a later stage of the illness. A commonly held but unsubstantiated belief is that artificial nutrition and hydration are comfort measures, without which a child may suffer from starvation or thirst. The sensation of thirst may be alleviated by careful efforts to keep the mouth moist and clean. There are also deleterious side effects to artificial hydration in the form of increased secretions, need for frequent urination, edema, and exacerbation of dyspnea. For these reasons, it is important to educate families about anticipated decreases in appetite/thirst and therefore little need for nutrition and hydration as the child approaches death. In addition, exploring the meaning that provision of nutrition and hydration may hold for families, as well as helping families anticipate the changes in their child's appearance and exploring alternative ways that they may love and nurture their child, may ease distress around this issue.

Nausea and vomiting may be caused by medications or toxins, irritation to or obstruction of the gastrointestinal tract, motion, and emotions. Drugs such as metoclopramide, 5-hydroxytryptamine antagonists, corticosteroids, olanzapine, and aprepitant may be used and should be chosen depending on the underlying pathophysiology and neurotransmitters involved. Vomiting may accompany nausea but may also occur without nausea, as with increased intracranial pressure. **Constipation** is commonly encountered in children with neurologic impairment or children receiving medications that impair gastrointestinal motility (most notably opioids). Stool frequency and quantity should be evaluated in the context of the child's diet and usual bowel pattern. Children using scheduled opioids should routinely be placed on an osmotic laxative (polyethylene glycol) in addition to a stimulant laxative agent (e.g., senna). For some patients, parenteral methylnaltrexone is also helpful in relieving opioid-induced constipation. **Diarrhea** may be particularly difficult for the child and family and may be treated with loperamide (an opioid that does not cross the blood-brain barrier), and in some cases, cholestyramine or octreotide may be indicated. Paradoxical diarrhea, a result of overflow resulting from constipation, should also be included in the differential diagnosis.

Hematologic issues include consideration of anemia and thrombocytopenia or bleeding. If the child has symptomatic anemia (weakness, dizziness, shortness of breath, tachycardia), red blood cell transfusions may be considered. Platelet transfusions may be an option if the child has symptoms of bleeding. Teabags on the gums and topical agents such as Amicar may be used for mucosal bleeding. It is important to provide anticipatory education that although distressing to see, bleeding is not painful. Life-ending hemorrhage is disturbing for all concerned, and a plan involving environment intervention such as dark sheets and the use of fast-acting sedatives should be prepared in advance if such an event is a possibility.

Skin care issues include primary prevention of problems by ongoing and timely assessment (including observation of indwelling lines and tubes) and frequent turning and repositioning and alleviating pressure wherever possible (e.g., elevating heels off the bed with pillows). Pruritus may be secondary to systemic disorders or drug therapy. Treatment includes avoiding excessive use of drying soaps, using moisturizers, trimming fingernails, and wearing loose-fitting clothing, in addition to administering topical or systemic corticosteroids. Oral antihistamines and other specific therapies may also be indicated (e.g., cholestyramine in biliary disease). Opioids can cause histamine release from mast cells, but this does not account for most of the pruritus caused by opioids. Given that opioid-induced pruritus is generally not histamine-mediated, the mainstay of treatment includes rotating opioids or instituting a low dose of opioid antagonist (nalbuphine or naloxone) rather than an antihistamine.

Children with life-threatening illness may experience psychologic symptoms such as **anxiety** and **depression**. Such symptoms are frequently multifactorial and sometimes interrelated with uncontrolled symptoms such as pain and fatigue. Diagnosing depression in the context of serious illness may pose challenges because neurovegetative symptoms may not be reliable indicators. Instead, expressions of hopelessness, helplessness, worthlessness, and guilt may be more useful. Interventions and opportunities for children to explore worries, hopes, and concerns in an open, supportive, and nonjudgmental setting are equally, if not more, important approaches to psychologic distress. Skilled members from a variety of disciplines, including psychology, social work, chaplaincy, child life, and expressive therapy, may help children and their families in this regard. Such opportunities may

create positive moments in which meaning, connection, and new definitions of hope are found. Pharmacologic agents such as antidepressants may be helpful, although their effect is often preceded by a significant lag phase. Because of its immediate and positive effect on mood, *methylphenidate* may be an effective antidepressant for children at the end of life, when there may not be time for a traditional antidepressant to take effect.

Discussions with adolescent patients, or with the parents of any ill child, about possible therapies or interventions should include **integrative therapies** such as massage therapy, Reiki, acupuncture, clinical aromatherapy, prayer, and nutritional supplements. Many families use integrative therapy but do not bring it up with their physician unless explicitly asked (see Chapter 7). Although largely unproven, some of these therapies are inexpensive and provide relief to individual patients. Other therapies may be expensive, painful, intrusive, and even toxic. By initiating a conversation and inviting discussion in a nonjudgmental way, the clinician can offer advice on the safety of different therapies and may help avoid expensive, dangerous, or burdensome interventions. Medical marijuana (**cannabis**) for pediatric use has been legalized by some states, and pediatricians are increasingly asked about it. In such cases, it is most helpful to use this opportunity to engage in a broader conversation about symptoms and symptom management, even in states where use of cannabis for pediatric medicinal purposes is legal.

Intensive Symptom Management

At the end of life, when intensive efforts to relieve the symptom have been exhausted, or when efforts to address suffering are incapable of providing relief with acceptable toxicity/morbidity or in an acceptable time frame, **palliative sedation** may be considered. Palliative sedation may relieve suffering from refractory symptoms by reducing a child's level of consciousness. It is most often used for intractable pain, dyspnea, or agitation, but is not limited to these distressing indications. It is imperative that parents, staff, and primary clinicians discuss the indications and goals for sedation before initiation of this therapy, as well as questions or concerns about this therapy, and to engage in ongoing discussions after initiation of sedation.

The doctrine of double effect (DDE) is often invoked to justify escalation of symptom-relieving medications or palliative sedation for uncontrolled symptoms at the end of life. Use of DDE emphasizes the risk of hastening death posed by escalating opioids or sedation, which is theoretical and unproven (see Chapter 6). There is mounting evidence that patients with well-controlled symptoms live longer.

Approaching End of Life and Bereavement

As death seems imminent, the major task of the physician and team is to help the child have as many good days as possible and not suffer. If patient and family preference is to remain at home and clinical status and community supports allow this, if not already in place, a referral **for hospice care** (usually provided in the *home,* rather than a hospice facility) may provide the most comprehensive care for the child and family. Gently preparing the family for what to expect and offering choices, when possible, will allow them a sense of control in the midst of tragic circumstances. Before death, it can be very helpful to discuss the following:

- ◆ Support of siblings or other family members
- ◆ Resuscitation status
- ◆ Limiting technology when no longer beneficial to the child
- ◆ Cultural, spiritual, or religious needs
- ◆ Location of death
  - Who will pronounce if death occurs at home
  - Offering siblings choice and appropriate support to attend
- ◆ Autopsy and/or tissue/organ donation
  - Builds a legacy, benefits others, and informs science and family

Offered the opportunity, families will often tolerate thinking and speaking about their hopes and fears regarding their child's end of life, and some even express relief when the door to such a conversation is opened by the care team. It may help to let the family know these conversations are not about *whether* the child will die, but *how* the child may die.

Families gain tremendous support from having a physician and team who will continue to stay involved in the child's care. If the child is at home or hospitalized, regular phone calls or visits, assisting with symptom management, and offering emotional support is invaluable for families.

In an intensive care setting, where technology can be overwhelming and put distance between the child and parent, the physician can offer discontinuation of that which is no longer benefiting the child or adding to quality of life. Less invasive ways to control symptoms, such as subcutaneous infusions or topical applications, may be helpful. Parents may be afraid to ask about holding their child or sleeping next to their child. They may need reassurance and assistance in holding, touching, and speaking with their child, despite tubes and technology, even if the child appears unresponsive.

It is believed that hearing and the ability to sense touch are often present until death; all family members should be encouraged to continue interacting with their loved one through the dying process as they feel comfortable. Parents may be afraid to leave the bedside so that their child will not die alone. Offering parents other supports such as chaplaincy/clergy, social work, and extended family members may be helpful. In most instances the moment of death cannot be predicted. Some propose that children wait to die until their parents are ready, an important event has passed, or they are given permission. The care team need not dispute this, nor the hope for a miracle often held by families until the child takes the last breath.

For the family, the moment of death is an event that is recalled in detail for years to come, and thus enhancing opportunity for dignity and limited suffering is essential. Research suggests that improved symptom control and easing of difficult moments at the time of death may lessen the long-term distress of bereaved parents. Clinical experience has shown that families often find solace in clinician presence, whether at home or in the hospital. After death, families should be given the option of remaining with their child for as long as they would like and should be prepared for changes in the child's body. During this time, physicians and other professionals may ask permission to say goodbye. The family may be invited to bathe and dress the body as a final act of caring for the child.

The clinician's decision to attend the funeral is a personal one. Participation may serve the dual purpose of showing respect and helping the provider cope with a personal sense of loss. If unable to attend services, families report highly valuing the importance of receiving a call, card, or note from the physician. To know that their child made a difference and will not be forgotten is often very important to families in their bereavement. Furthermore, bereaved parents cite ongoing support from their child's healthcare teams and medical institutions after the death of their child as essential sources of support during their grief journeys. Many families benefit from community-based bereavement support groups, which are often offered through hospice organizations, or individual grief counseling.

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Chapter 9

Domestic and International Adoption

Elaine E. Schulte

Adoption is a social, emotional, and legal process that provides a new family for a child when the family of origin is unable or unwilling to parent. In the United States, about 1.5 million children <18 years of age are adopted; 2–4% of American families have adopted. In the United States, approximately 135,000 children are adopted every year. Of these, 59% are from the child welfare (foster) system, 25% are from other countries, and 15% are voluntarily relinquished American babies. The remaining numbers are from private agencies, American Indigenous Nations, stepparent, or other forms of kinship care. Because of changing policies toward adoption and social change in several of the sending countries, the number of international adoptions has decreased dramatically over the last 15 years. Public agencies support approximately 50% of total annual adoptions in the United States, private agencies facilitate 25% of adoptions, and independent practitioners (e.g., lawyers) handle 15% of adoptions. Compared to 19% of the general population, approximately 39% of adopted children have special healthcare needs.

DOMESTIC ADOPTION

The **Adoption and Safe Families Act** (P.L. 105-89) requires children in foster care to be placed with adoptive families if they cannot be safely returned to their families within a reasonable time. In fiscal year (FY) 2020 there were an estimated 407,000 children in foster care and 117,000 waiting for adoption. Of the 224,000 who exited foster care, 48% were reunited with parent(s) or primary caretaker(s) and 25% were adopted. Of the 53,500 children who were adopted in 2021, 55% were adopted by their foster parent(s) and 34% were adopted by relatives (see Chapter 10).

Many children awaiting adoption are less likely to be adopted because they are of school age, are part of a sibling group, are members of historically oppressed racial/ethnic groups, or have considerable physical, emotional, or developmental needs. A number of policy efforts are aimed at increasing adoption opportunities for these children, including federal adoption subsidies, tax credits, recruitment efforts to identify ethnically diverse adults willing to adopt, increased preplacement services, and expanding adoption opportunities to single adults, older couples, and gay/lesbian partners.

Same-sex couple adoption is legal in more than a dozen countries worldwide. Although legislation regarding same-sex couple adoption varies by state, increasing numbers of gay and lesbian partners have been able to adopt. Current estimates suggest that over 2 million children, including 5% of all adopted children, are raised by gay or lesbian parents. Adopted children include those adopted domestically, those from foster care, and internationally adopted children. There is good evidence that children raised by same-sex couples are as physically or psychologically healthy, capable, and successful as those raised by opposite-sex couples. Pediatricians can advocate for adopted children by supporting gay and lesbian parents.

Open adoption, usually through an agency or privately, occurs when the birth mother arranges to continue to be involved, although in a limited manner, with the legally adopted family. This may occur through surrogacy or, more often, in an unplanned pregnancy.

INTERCOUNTRY ADOPTION

Along with foster care adoptions, **international adoptions** are a way of providing stable, long-term care to vulnerable children throughout the world. There is concern that in some countries of origin, the rapid growth of international adoption has outpaced regulation and oversight to protect vulnerable children and families. Opportunities for financial gain have led to abuses, including the sale and abduction of children, bribery, and financial coercion of families, but the extent and scope of the potential concern are difficult to ascertain. Increasing global efforts, such as the **Hague Convention on Protection of Children and Co-operation in Respect of Intercountry Adoption**, have promoted political cooperation between nations and established international law to reduce the potential for child abduction and child trafficking and to ensure that the best interests of the child are paramount in decision-making. Participating nations, including the United States, are working to address the myriad of sociopolitical conditions that create the need for out-of-family care and are working to support children within their nation's borders. International adoption is increasingly considered a measure of last resort if the child cannot be cared for within his or her family of origin (including extended relatives), the immediate community, or the larger national culture. As a result, children adopted internationally into the United States are more likely to enter their families at older ages or with complex medical, developmental, or social-emotional needs.

In 2021, US families adopted 1,785 children from other countries (compared to a peak of 22,884 in 2004). Children from Bulgaria, Columbia, India, Nigeria, South Korea, and Ukraine represented 65% of children adopted internationally into the United States; 2021 marked the first year since 1984 where no children where adopted from China. Although individual experiences vary, most children placed for international adoption have some history of poverty and social hardship in their home countries, and most are adopted from orphanages or institutional settings. Many young infants are placed into **orphanage care** shortly after birth. Some older children have experienced family disruption resulting from parental illness, war, or natural disasters. Still others enter orphanage care after determination of significant abuse or neglect within their biologic families. The effects of **institutionalization** and other life stresses may affect all areas of growth and development. As a result, many children require specialized support and understanding to overcome the impact of stress and early adversity and to reach their full potential.

ROLE OF PEDIATRICIANS

Preadoption Medical Record Reviews

Preadoption medical record reviews are important for both domestic and international adoptions. Adoption agencies are making increased efforts to obtain biologic family health information and genetic histories to share with adoptive families before adoption. Such information often becomes increasingly relevant as the child ages. The unique medical and developmental needs of adopted children have led to the creation of specialty clinics throughout the United States, which may be a valuable resource for adoptive families at all stages in the adoption process and throughout the adopted child's life. When available, adoption medicine pediatricians can help prospective adoptive parents understand the health and developmental history of a child and available background information from birth families in order to assess actual and potential medical and psychosocial risk factors to support adult decision-making about the family's ability to parent the waiting child.

Under the Hague Convention, U.S. agencies that arrange international adoptions must make efforts to obtain accurate and complete health histories on children awaiting adoption. The nature and quality of medical and genetic information, when available, vary greatly. Incongruous translation and use of medical terminology and medications that are unfamiliar to U.S.-trained physicians are common. Results of specific diagnostic studies and laboratory tests performed outside the United States should not be relied on and *should be repeated* once the child arrives in the United States. Paradoxically, review of the child's medical records may raise more questions than provide answers. Each medical diagnosis should be considered carefully before being rejected or accepted. Country-specific growth curves should be avoided because they do not reflect the demographic of institutionalized

Table 9.1 Recommended Screening Tests for International Adoptees on U.S. Arrival

SCREENING TESTS
Complete blood cell count, including eosinophil count
Thick and thin smear for malaria if from endemic area
Vitamin D level
TSH, T_4
Iron, ferritin
Blood lead level
Newborn universal screening (age ≤6 mo)
Vision and hearing screening
Dental screening
Developmental testing
Immunization records or titers (alternative plan: revaccinate)
OTHER SCREENING TESTS TO CONSIDER BASED ON CLINICAL FINDINGS AND AGE OF CHILD
Stool cultures or NAAT for bacterial pathogens in the presence of diarrhea and fever
Glucose-6-phosphate dehydrogenase deficiency (based on heritage)
Sickle cell test or hemoglobin electrophoresis (based on heritage)
Urine pregnancy test
INFECTIOUS DISEASE SCREENING
(see Table 9.2)

NAAT, Nucleic acid amplification test; TSH, thyroid-stimulating hormone.

Table 9.2 Infectious Disease Screening for Internationally Adopted Children

CONDITION OR TEST	INTERNATIONALLY ADOPTED CHILDREN
HEPATITIS A VIRUS (ACUTE INFECTION)	
Hepatitis A IgM antibody	All
HEPATITIS B VIRUS	
Hepatitis B surface antigen (HBsAg)	All[a]
Hepatitis B surface antibody (anti-HBs)	All[a]
Hepatitis B core antibody (anti-HBc)	All[a]
HEPATITIS C VIRUS	
Hepatitis C antibody	All[a]
SYPHILIS	
Nontreponemal test (RPR, VDRL, or ART)	All
Treponemal test (TPPA, MHA-TP, or FTA-ABS)	All
HUMAN IMMUNODEFICIENCY VIRUS	
Human immunodeficiency virus 1 and 2 antibody	All[a]
TUBERCULOSIS	
Tuberculin skin test (TST)	All[a]
or	
Interferon-γ release assay	≥2 yr
INTESTINAL PARASITES	
Microscopic evaluation of stool for ova and parasites	All (3 specimens)
Giardia intestinalis and *Cryptosporidium* antigen	All (1 specimen)
BACTERIAL ENTERIC INFECTION	
In children with diarrhea: bacterial stool culture	All
CHAGAS (ENDEMIC AREAS)	
Trypanosoma cruzi serologic testing	All
Complete blood count	All
EOSINOPHILIA WITH NEGATIVE STOOL OVA AND PARASITE FOR HELMINTHS	
Strongyloides serologic testing	All
Schistosoma serologic testing (endemic countries)[b]	
LYMPHATIC FILARIASIS (ENDEMIC AREAS)	
Filaria serology	≥2 yr
CHAGAS (ENDEMIC AREAS)	
Trypanosoma cruzi serologic testing	All
MALARIA SCREENING (ENDEMIC AREAS)	
Malaria polymerase chain reaction	Not recommended
HEMATURIA (SCHISTOSOMIASIS)	
Urinalysis	Not recommended

[a]Consider reassessing 6 months after arrival.
[b]Some experts recommend serologic testing regardless of whether eosinophilia is present.
ART, Automated reagin test; FTA-ABS, fluorescent treponemal antibody absorption; MHA-TP, microhemagglutination–*Treponema pallidum;* RPR, rapid plasma reagin; TPPA, *Treponema pallidum* particle agglutination; VDRL, Venereal Disease Research Laboratory.
https://wwwnc.cdc.gov/travel/yellowbook/2020/family-travel/international-adoption.

children. Instead, *serial growth* data should be plotted on U.S. standard growth curves; this may reveal a pattern of poor growth because of malnutrition or other chronic illness. Photographs or video files may provide the only objective information from which medical status can be determined. Full-face photographs may reveal dysmorphic features consistent with fetal alcohol syndrome (see Chapter 146) or findings suggestive of other congenital disorders.

Frank interpretations of available information should be shared with the prospective adoptive parents. The role of the healthcare provider is not to comment on the advisability of an adoption, but to inform the prospective parents of any significant medical, developmental, and behavioral health needs identified now or anticipated in the future.

Postadoption Medical Care

Arrival Visit: International Adoption

All internationally adopted children should have a thorough medical evaluation shortly after arriving in the United States. Many children may have acute or chronic medical problems that are not always immediately evident, including malnutrition, growth deficiencies, stool pathogens, anemia, elevated blood lead, dental decay, strabismus, birth defects, developmental delay, feeding and sensory difficulty, and social-emotional concerns. *All children who are adopted from other countries should undergo comprehensive screening for infectious diseases and disorders of growth, development, vision, and hearing* (Tables 9.1 and 9.2). Regardless of test results before arrival, all children should be screened for tuberculosis with either a tuberculin skin test (TST) or interferon-γ release assay (IGRA). If the child's purified protein derivative (PPD) skin test is negative, it should be repeated in 4-6 months; children may have false-negative tests because of poor nutrition. Additional tests (e.g., malaria) should be ordered depending on the prevalence of disease in the child's country of origin (see Chapter 11). **Immunization records** should be carefully reviewed. Internationally adopted children frequently have incomplete records or have been vaccinated using alternative schedules. Pediatricians may choose to check titers to determine which vaccines need to be given, or they can *choose to reimmunize* the child.

Growth Delays

Physical growth delays are common in internationally adopted children and may represent the combined result of many factors, such as unknown/untreated medical conditions, malnutrition, and psychologic deprivation. It is more important to monitor growth over time, including preplacement measurements, because trend data may provide a more objective assessment of the child's nutritional and medical status. Children who present with low height for age (**growth stunting**) may have a history of inadequate nutrition and chronic adversity. Although most children experience a significant catch-up in physical growth after adoption, many remain shorter than their peers who did not experience early adversity.

Developmental Delays

Many children adopted internationally exhibit delays in at least one area of development, but most exhibit significant gains within the first 12 months after adoption. Children adopted at older ages are likely to have more variable outcomes. In the immediate postadoption period, it may be impossible to determine with any certainty whether developmental delays will be transient or long-lasting. Careful monitoring of development within the first years of adoption can identify a **developmental trend** over time that may be more predictive of long-term functioning than assessment at any specific point in time. When in doubt, it is better to *refer early* for developmental intervention, rather than wait to see if the children will catch up (see Chapter 28).

Language Development

For both domestic and international adoptees, genetic or biologic risk factors for poor language development may be identified preadoptively, but it is unlikely that international adoptees will have had these delays identified before adoption. These children typically have not had an assessment in their native language and have had little exposure to English. If assessment in their native language is not available, it may not be possible to fully assess their language abilities until they have had a chance to learn English. Regardless of the age at adoption, most internationally adopted children will reach age-expected language skills over time.

If a child has language delays, referral to early intervention or the school district should be made. Clinicians may need to work with these groups to help them understand the unique circumstances surrounding an adopted child's language development. For example, English language acquisition in internationally adopted children depends on the age of adoption and native language skills. Placing the recently adopted, school-age child in an English as a second language class may not be sufficient if the child's language development in the primary language has been atypical.

Eating Concerns

Initial concerns about eating, sleep regulation, and repetitive (e.g., self-stimulating or self-soothing) behaviors are common, especially among children adopted after a high degree of neglect or developmental trauma. Feeding behaviors of international adoptees may be linked to orphanage feeding practices or limited exposure to textured or solid foods during later infancy/toddlerhood. Children who have experienced chronic lack of food may not have developed an awareness of *satiation cues,* leading to hoarding or frequent vomiting. **Feeding concerns** often subside gradually with introduction of age-appropriate foods and parental support for positive feeding practices. Many children who were adopted after significant malnutrition may eat an excessive amount of food. Unless the child is eating to the point of vomiting (which would indicate little awareness of satiation cues), it is generally best to allow them to eat until satiation. Typically, within several months, the child will regulate food intake appropriately. Occasionally, additional support from a speech pathologist or feeding specialist is warranted to address possible sensory, physical, or psychologic issues around proper feeding.

Sleep Concerns

Sleep is often disrupted as the child reacts to changes in routines and environments. Efforts to create continuity between the preadoption and postadoption environment can be helpful. Within the first 3-6 months, as the child's emotional self-regulation improves, many sleep concerns subside. Similarly, stereotypical behaviors, such as rocking or head banging, often diminish within the first few months after adoption.

Social and Emotional Development

Dyadic interactions between child and caretaker are a critical component to later regulatory functioning and social-emotional development. The amount and quality of individualized caretaking that children have received before their adoption, whether international, domestic, or through the foster care system, is usually unknown. In many cases, entry into a secure, stable home setting with consistent childcare routines is sufficient to support the child's emerging social-emotional development. Pediatricians can help parents remember that adoption is part of the child's identity. Throughout one's childhood, prior experiences or biologic disposition may result in behavior that is confusing to the adoptive parents. The child's reactions may be subtle or difficult to interpret, interfering with the parents' ability to respond in a sensitive manner. In these circumstances, additional behavioral health support may be helpful to foster the emerging relationships and behavioral regulation in the newly formed family.

Racial Identity Development

Transracial adoption (where the racial background of the child differs from that of the parent/parents) accounts for a significant percentage of adoptions each year in the United States. In most of these adoptive placements, children of color have been adopted by White parents. Racial identity development, including ways to understand and respond to discrimination, is increasingly recognized as important in the overall development of children. Surveys of adults adopted transracially indicate that racial identity is of central importance at many ages and tends to increase in significance during young adulthood. Integrating race/ethnicity into identity can be a complex process for all children, but it may be especially complicated when they are raised in a family where racial differences are noted. Adults raised within interracial families have noted the value of attending racially diverse schools and of having adult role models (e.g., teachers, doctors, coaches) who share their racial background. Parents who adopt transracially are often encouraged to support interactions within diverse communities and to discuss race (and associated discrimination) often within the family. Black children raised by White families in White communities may have been sheltered from overt racism but need to be taught that many others (including law enforcement officers) will regard them as Black with all the intense biases associated with race (see Chapter 2.1).

Adoption culture camps are another option for transracial Black children to experience their racial heritage and meet children with similar experiences. In addition, there are Asian (Chinese, Korean) heritage camps that provide a similar cultural experience for internationally adopted children.

Toxic Stress

The cumulative amount of unsupported early adversity (e.g., numerous years within international orphanage care, extensive abuse/neglect before removal from the biologic family, or multiple foster care placements) experienced by a child before adoption, referred to as *toxic stress,* can affect both immediate placement stability and long-term physical health and emotional well-being (see Chapter 2). The degree of presumed toxic stress may be helpful in interpreting a child's behavior and supporting family functioning.*

Family Support

The unique aspects to adoptive family formation can create familial stress and affect child and family functioning. Some adoptive families may have to address infertility, creation of a multiracial family, disclosure of adoptive status, concerns and questions the child may have about their preadoptive experiences and biologic origins, and ongoing scrutiny by adoption agencies. With gay/lesbian parents, there are often additional psychosocial stressors, including continued barriers to legal recognition of both parents in a gay/lesbian partnership that can negatively affect family functioning. Although most families acclimate well to adoption-related stressors, some parents experience postadoption depression and may benefit from additional mental health support to ease the family's transition.

Adoption Narrative

Families are encouraged to speak openly and repeatedly about adoption with their child, beginning in the toddler years and continuing through adolescence. Creating a *lifebook* for the adopted child provides a way to support family communication about the child's

* See video at https://www.youtube.com/watch?v=rVwFkcOZHJw

history and significant relationships (including members of the family of origin) and to document the child's important life transitions (e.g., through foster care or immigration to the United States). It is common, and normal, for children to have questions about adoption and their preadoptive experiences and biologic family throughout their development. An increase in cognitive understanding between ages 7 and 10 years can sometimes increase adoption-related questions and distress. Youth who have questions about biologic family members are increasingly able to access information via social media and web-based searching, raising the importance of ongoing open communication about adoption. Pediatricians may need to respond to increased concerns and questions when the adoptee's health and genetic history is incomplete or unknown. It is important to remember that, at any time, concerns about development, behavior, and social-emotional functioning may or may not be related to the child's adoption history.

The vast majority of adopted children and families adjust well and lead healthy, productive lives. Adoptions infrequently disrupt; disruption rates are higher among children adopted from foster care, which research associates with their age at adoption and a history of multiple placements before adoption. With increased understanding of the needs of families who adopt children from foster care, agencies are placing greater emphasis on the preparation of adoptive parents and ensuring the availability of a full range of postadoption services, including physical health, mental health, and developmental services for their adopted children.

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Chapter 10

Foster and Kinship Care

Mary V. Greiner, Heather C. Forkey, and Moira Szilagyi

The placement of children in out-of-home care has served the needs of children in many societies worldwide throughout history. The institution of foster care was developed in the United States as a temporary resource for children during times of family crisis and is rooted in the principle that children fare best when raised in family settings. The mission of foster care is to provide for the safety, permanency, and well-being of children while assisting their families with services to promote reunification.

EPIDEMIOLOGY

The number of children in foster care worldwide is unknown, although it has been estimated that 8 million may be in foster and **congregate care**. On September 30, 2021, approximately 391,098 children in the United States resided in foster care, down from a high of 511,318 in care in 2005. Early in the millennium, foster care numbers decreased despite an increase in maltreatment reports, as child welfare offered families more preventive services and placement with relatives (**kinship care**) or nonrelative caregivers as an alternative to court-ordered removal. Higher rates of children in care, reaching 437,337 in 2018, appear to be related to the opioid epidemic. Over the last 10 years, reunification rates and adoption of children from foster care have increased. Nationally, approximately 44% of children live with a nonrelative foster caregiver, 35% of children are in placement with a relative, 9% are in congregate (group) care, and 2% are in supervised independent living.

Approximately 37% of children in foster care in the United States are younger than 5 years, and 28% are older than 12 years. Most children are White (44%), 22% are Black, 22% are Hispanic of any race, and 8% are identified as 2 or more races. Child welfare agencies have been attending to the drivers of disparities rooted in implicit bias and structural racism for nearly 2 decades. Despite efforts to address disparities, Black, Latinx, and Indigenous children are overrepresented in foster care compared with their representation in the population at large. The average length of stay in foster care continues to decline (median in 2021, 14.9 months), though 33% of children spend >2 years in care as of 2021. Approximately half of children achieve reunification, and 25% are adopted and 9% reside with relatives. Among the remaining children, 8% emancipate between ages 18 and 21. There were 368 deaths reported in foster care in FY 2021.

Placement instability (multiple placements) is associated with poor outcomes for children in foster care, including poor educational outcomes and increased behavioral and mental health issues as well as delayed permanency (i.e., reunification, adoption). The majority of children in foster care for longer than 2 years have three or more placements. Important predictors of multiple placements include older age, longer time in custody, history of sexual or physical abuse, and behavioral and physical health challenges.

Youth who emancipate (e.g., age out) from foster care face additional challenges. Approximately 75% have graduated from high school or obtained a GED. By age 24, only 5% have graduated from any 2- or 4-year college and only half are employed. 39% have experienced homelessness or "couch surfing." 81% of males and 57% of females have been arrested. Two thirds of females and one half of males report they have had at least one child. Extended foster care to age 21 benefits youth in foster care, although it does not eliminate all risks.

LEGISLATION IN THE UNITED STATES

In the United States, the **Adoption and Safe Families Act** (P.L. 105-89) requires that a permanency plan be made for each child no later than 12 months after entry into foster care and that a petition to terminate parental rights typically be filed when a child has been in foster care for at least 15 of the previous 22 months. The **Fostering Connections and Promoting Adoptions Act** of 2009 (P.L. 110-351) focused on incentives for guardianship and adoption, supports for young adults at the age of emancipation, and rights of U.S. Indigenous Nation children to caregiving within their tribe. This act also contained a clause requiring states to develop and coordinate healthcare systems for children in foster care in collaboration with Medicaid and pediatricians. In 2018 the **Family First Prevention Services Act** was signed into law. This legislation emphasizes providing evidence-based mental health and substance abuse services for families whose children are at imminent risk of entering foster care, addresses the need for children in care to be provided with appropriate evidence-based mental health services, and has incentives to move children in care from congregate to family settings.

EARLY CHILDHOOD TRAUMA LEADS TO POOR HEALTH OUTCOMES

Children in foster care have high rates of **early childhood trauma** and adversity. More than 60% are placed in foster care for neglect, 12% for physical abuse, 4% for sexual abuse, and 5% are abandoned. Parental alcohol and other **substance use** is a known factor in 42% of removals and are likely underestimated. Parental alcohol and substance use also contributes to prenatal substance exposures for their children. **Violence** in the home is common, with many children having experienced intimate partner and/or community violence.

Removal from the family of origin may compound prior trauma experiences, although some children experience relief at removal from a chaotic, abusive, or dangerous home. No matter the circumstances of removal, most children miss their family, worry about their family, and long for reunification. Separation, loss and grief, unpredictable contact with family of origin, placement changes, the process of terminating parental rights, and the sheer uncertainty of foster care may further erode a child's well-being.

Childhood trauma is correlated with poor developmental, behavioral, and health outcomes. Early trauma and chronic stress adversely affect the neurobiology of the developing brain, especially those areas involved in attention, emotional regulation, memory, executive function, and cognition. As a result, shortened attention span, hyperactivity or dissociation, poorer cognitive function, aggression, and memory issues are problems encountered frequently among children in foster care. Evidence-based mental health trauma treatment is recommended for children who are symptomatic. Additionally, evidence shows that foster care–specific interventions, such as specially trained foster caregivers and mentoring for adolescents in foster care, can improve outcomes, although replication and dissemination of these evidence-based interventions is limited.

HEALTH ISSUES

Experiencing multiple childhood adversities and receiving fragmented and inadequate health services before placement into foster care mean that children enter foster care with a high prevalence of chronic medical, mental health, developmental, dental, and educational problems. Thus they are defined as *children with special healthcare needs* (CSHCN). The greatest single healthcare need of this population is for high-quality, evidence-based, **trauma-informed** mental health services to address the impacts of prior and ongoing trauma, loss, and unpredictability. In addition, children in foster care have higher rates of asthma, growth failure, obesity, vertically transmitted infections, hearing and vision loss, dental decay, and neurologic conditions than the general pediatric population. Adolescents need access to reproductive health and substance use services. Up to 60% of children <5 years old have a developmental delay in at least one domain, and >40% of school-age children qualify for special education services. Unfortunately, educational difficulties persist despite improvements in school attendance and performance after placement in foster care. Each placement change that is accompanied by a change in school sets children back academically by about 4 months. Federal legislation requires child welfare to maintain children in their school of origin when possible, even if child welfare has to provide transportation to ensure this.

Although children in foster care are CSHCN, they often lack access to the services they need. Most public and private child welfare agencies do not have formal arrangements for accessing the needed array of health services and rely on local physicians and health clinics funded by Medicaid. Health histories are often sparse at admission because many have lacked regular care, or their family of origin may not be available, and information sharing between medical and child welfare settings is often very limited. Once children enter foster care, there is often a diffusion of responsibility for obtaining healthcare services across caregivers and child welfare. Foster caregivers usually receive little information about a child's healthcare needs, but they are typically expected to decide when and where children receive medical treatment. Child welfare professionals are responsible for ensuring that a child's health needs are addressed, but coordination across multiple healthcare providers can be daunting. Although child welfare can consent to routine care and even some procedures, the child's parents or family of origin may retain some medical decision-making rights unless parental rights have been terminated. Complexity in legal responsibility for making healthcare treatment decisions and access to health information may delay or result in the denial of healthcare services.

HEALTHCARE FOR CHILDREN AND ADOLESCENTS IN FOSTER CARE

The American Academy of Pediatrics (AAP) has published detailed healthcare standards for children in foster care, available on the *Healthy Foster Care America* website. The AAP recommends that children receive healthcare services in a medical home setting, where comprehensive healthcare is continuous over time. Compassionate, culturally competent healthcare that is trauma-informed means that health staff should understand, recognize, and respond to symptoms and risk factors of traumatic stress and provide an environment that offers physical, emotional, and psychologic safety for children and caregivers. In foster care, attention must be paid to the effects of past trauma and the impact of ongoing uncertainty and loss on a child's health and well-being, as well as that of their birth and foster/kinship caregivers.

The **trauma-informed office** is one in which symptoms such as dysregulation of sleep, behavioral problems, developmental delays, poor school function, and somatic complaints are recognized as potential effects of childhood trauma. Understanding the child's psychosocial context and history, as well as that of the caregiver, and exploring their strengths, assets, and challenges are the foundation of a trauma-informed approach. The office should have resources for education of families and child welfare professionals and ideally the ability to make warm hand-offs to community resources. Integrated trauma-informed pediatric mental health services are ideal, with referrals to community mental health services when needed, in collaboration with caregivers, child welfare, and educators. **Continuity of care** is very important for the child in foster care and includes ongoing monitoring and management of progress and care.

Several recommendations are specific to the care of children and youth in foster care (Table 10.1). Children should be seen early and often when they first enter a new placement to identify all their health issues and to support the child and caregivers through a major transition that involves considerable loss and adjustment, including the development of an attachment relationship with a new caregiver and the promotion of the child and family of origin relationship.

It is recommended that every child in foster care have comprehensive medical, dental, developmental, and mental health assessments within 30 days of entering foster care. Almost every child in foster care deserves a full mental health evaluation to assess for the impact of trauma and loss on emotional well-being. *Psychotropic medication* should only be considered, after a thorough, high-quality, trauma-informed mental health evaluation by a pediatric-trained mental health professional. The healthcare provider should remember that the impact of trauma on the developing brain can mimic other mental health disorders, including attention-deficit/hyperactivity disorder, anxiety, and depression (see Chapters 38, 39, and 50). Childhood trauma may impair cognition, executive function, and memory (see Chapter 49), so that children <6 years of age benefit from a comprehensive developmental assessment, whereas older children often benefit from a comprehensive psychoeducational assessment. The child welfare professional should provide consents for healthcare and any available health history and encourage the appropriate involvement of the family of origin. This can be facilitated with electronic medical records, though multiple sources of information may need to be identified, as most children have experienced fragmented care. The primary care provider can help child welfare professionals and caregivers by obtaining and interpreting the results of these assessments. Pediatricians, caregivers, and child welfare professionals should share information to ensure the best healthcare delivery.

Foster/kinship caregivers are the major therapeutic intervention of the foster care system, and pediatricians are in a unique position to provide them with appropriate education and support. Important topics include positive parenting strategies, supporting children through transitions, providing a consistent and nurturing environment, and helping children heal from past trauma and adversity (Table 10.2). All caregivers may need extensive education

Table 10.1 Healthcare Needs and Guidance for Pediatricians Caring for Children in Foster Care

HEALTH NEED	HEALTHCARE RISKS	GUIDANCE FOR PEDIATRICIANS
Health supervision Physical health and growth Nutrition Vision/hearing Immunizations Anticipatory guidance	Food insecurity and malnutrition, leading to poor growth (failure to thrive) or obesity Vision/hearing deficits Behind on immunizations or overvaccinated with poor records Increased lead exposures Increased communicable diseases	See early and often with entry into foster care and placement changes, screening within the first week, and comprehensive evaluation within 1 mo After stabilization, visits every month for first 6 mo of age; every 3 mo from 6 mo to 2 yr; twice yearly after age 2 Support child, caregivers at placement, and family of origin Communicate and collaborate with child welfare professionals and legal professionals Maintain a comprehensive medical record despite changes in placement
Evaluation and monitoring for abuse/neglect	History of abuse and neglect at entry into foster care Abuse/neglect during out-of-home placement	Examine and document full physical examination, including skin, joint range of motion, and genital examination Laboratory testing for sexually transmitted infections (STIs), pregnancy, consideration of history of commercial sexual exploitation
Oral health	Poor dental hygiene Untreated dental disease	Examine teeth, apply fluoride when applicable, teach oral hygiene Connect with dental services by first birthday or first tooth, whichever comes first
Developmental delay/academic concern	Early adversity and environmental exposures with decreased supports lead to decreased rates of kindergarten readiness, literacy, and high school graduation School disruptions with placement changes	Developmental screening with low threshold for referral to early intervention and developmental therapies Recommend preschool programming (i.e., Head Start) and early education programs Clarification of ability to stay in school of origin (best interests determination), role of foster caregiver or education surrogate with role in requesting and approving educational plan Support child in obtaining IEP/504 plans for learning and/or behavior when needed
Mental health concerns	Placement into foster care is a trauma on top of whatever trauma that child has already experienced Placement disruptions cause further trauma Increased rates of mental health diagnoses Overlap/overrepresentation with juvenile justice	Maintain a trauma-informed medical office: Understand and educate children, families, and other healthcare professionals on the impact of early childhood adversities, trauma, and ongoing uncertainties of foster care on the developing child All children in foster care should have mental health evaluations, including screening for trauma symptoms Integrate pediatric care with behavioral health when possible Close psychiatric medication monitoring to prevent overuse; any medication should be accompanied by trauma-informed therapy Immediate referral for psychiatric emergency (i.e., suicide or violent behavior)
Medical complexity	Face challenges with chronic disease management caused by disruptions in care May be dependent on medical technologies Information sharing with foster caregiver and child welfare can improve care, follow-up	Need medical home to serve as hub for involved specialties Education required for child welfare professional to understand needs Extra care must be taken with placement changes to ensure appropriate medications, supplies, technology, etc., move with child and new caregivers are trained and prepared to meet needs; information sharing and transfer of medical information to be considered Assist with supports (e.g., SSI, special education)
Transition to adulthood	Adolescents more likely to be in nonfamilial settings, such as group homes and independent living with less adult support Sexual health risks, including earlier sexual debut and earlier transition to parenting Substance use risks, earlier initiation At risk for disengagement with healthcare system	Identify supports, such as mentors and educational/employment opportunities (i.e., Job Corps) Regular STI screening to include contraception and safe sex ounseling with support for LGBTQ+ individuals Screen for intimate partner violence Regular substance use screening with brief intervention and/or referral to treatment when appropriate Partner with adolescent medicine and transition medicine when available Support youth in foster care who are parents Warm handoff to adult healthcare providers to avoid disruptions

Table 10.2 Trauma-Informed Anticipatory Guidance for Children in Foster Care

SITUATION	ANTICIPATORY GUIDANCE FOR FOSTER CAREGIVERS
Preparing for visits with family of origin	Educate foster/kinship caregivers about impact of visitation on children and ways to improve the experience for children Create standard routines before visit Send familiar object with child to visit Have child draw picture or card to give family of origin Reassure child that foster/kinship caregiver will be there when child returns from visits Advise all caregivers to minimize conflict with and negativity toward each other Ideally, visits with family of origin are coached by trained professionals
Returning from visits and other transitions	Greet child warmly and help with unpacking Reassure safety with welcoming words, creating safe spaces in home (tent in the child's room, child's own special chair, lovey object) Establish reentry rituals, such as quiet play, reading together, active play, having a healthy snack
Relationship with family of origin	Encourage child welfare professional to have family of origin keep child's rituals and routines consistent with those in foster/kinship home (vice versa when appropriate) Focus on family of origin's positive qualities; maintain a neutral or positive affect
Affirming and building on child's strengths	Encourage participation in child-directed play Time-in with child Encourage participation in normalizing activities (e.g., hobbies, sports) "Catch the child being good," praising positive behaviors Give specific praise Practice attentive listening Provide child with words for emotions Ignore negative behavior or redirect unless there is a safety issue
Preparing for court dates	Foster/kinship caregiver, child welfare professional or law guardian should explain purpose of court hearings to child in simple terms Anticipate that court outcomes may disrupt child and reassure safety; return to routines as quickly as possible
School	If changing schools, visit school together a few times and meet teacher Check in regularly (weekly or monthly depending on need) with child's teacher Address need for any additional evaluation and supports, including IEP or specialized setting
Adolescence	Identify what issues demand firm limits and guidelines (e.g., curfews, no smoking, party at a friend's house), what issues are not important and can be left up to teen (e.g., hair length and color), and what issues are ideal for negotiation (e.g., transportation to school function, style of dress) Encourage responsible decision-making by recognizing and complimenting it Encourage and support after-school activities Teach driving when age and developmentally appropriate Encourage teen to seek employment and teach job skills Support skills in financial awareness and money management Help teen to identify mentors and focus on the future

about behavioral and emotional problems within the context of the child's trauma history to remove blame and promote healing. Minimizing conflict among parents/caregivers is extremely important because children ideally have affection and loyalty for all their caregivers. Clinicians can promote resilience by focusing on child, caregiver, and family of origin strengths. For teens and young adults in foster care, the pediatrician can provide anticipatory guidance around education, identity formation in the face of past trauma, independent decision-making, health promotion including reproductive health, healthy relationships, and developing the skills and competencies needed for a successful future life. The pediatrician can advocate for placement stability in a nurturing and responsive family setting where caregivers possess the appropriate skills to help children and youth heal.

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Chapter 11

Medical Evaluation of the Foreign-Born Child

Stacene R. Maroushek

More than 210,000 foreign-born children (≤16 years old) enter the United States each year as asylees (asylum seekers), refugees, and immigrants, including international adoptees (see Chapter 9). This number does not include undocumented children living and working in the United States, the U.S.-born children of foreign-born parents, or the approximately 2.7

million nonimmigrant visitors ≤16 years old who legally enter the United States annually with temporary visas. With the exception of internationally adopted children, pediatric guidelines for screening these newly arrived children are sparse. The diverse countries of origin and patterns of infectious disease, the possibility of previous high-risk living circumstances (e.g., refugee camps, orphanages, foster care, rural/urban poor), the limited availability of reliable healthcare in many economically developing countries, the generally unknown past medical histories, and interactions with parents who may have limited English proficiency and/or varied educational and economic experiences make the medical evaluation of immigrant children a challenging but important task.

Before admission into the United States, all immigrant children are required to have a medical examination performed by a physician designated by the U.S. Department of State in their **country of origin**. This examination is limited to completing legal requirements for screening for certain communicable diseases and examination for serious physical or mental problems that would prevent issuing a permanent residency visa. This evaluation is *not* a comprehensive assessment of the child's health, and except in limited circumstances, laboratory or radiographic screening for infectious diseases *is not required* for children <15 years old. After entry into the United States, health screenings of refugees, but not other immigrants, are recommended to be done by the resettlement state. There is limited tracking of refugees as they move to different cities or states. Thus many foreign-born children have had minimal prearrival or postarrival screening for infectious diseases or other health issues.

Immunization requirements and records also vary depending on entry status. Internationally adopted children who are younger than 10 years are exempt from Immigration and Nationality Act regulations pertaining to immunization of immigrants before arrival in the United States. Adoptive parents are required to sign a waiver indicating their intention to comply with U.S.-recommended immunizations, whereas older immigrants need only show evidence of up-to-date, not necessarily complete, immunizations before application for permanent resident (green card) status after arrival in the United States.

Infectious diseases are among the most common medical diagnoses identified in immigrant children after arrival. Children may be asymptomatic; therefore diagnoses must be made by screening tests in addition to history and physical examination. Because of inconsistent perinatal screening for hepatitis B and hepatitis C viruses, syphilis, and HIV and the high prevalence of certain intestinal parasites and tuberculosis, all foreign-born children should be screened for these infections on arrival in the United States. Table 9.2 and Table 11.1 list suggested screening tests for infectious diseases for international adoptees or immigrants/refugees, respectively. Table 11.2 lists incubation periods of common internationally acquired diseases. In addition to these infections, other medical and developmental issues, including hearing, vision, dental, and mental health assessments; evaluation of growth and development; nutritional assessment; lead exposure risk; complete blood cell count with red blood cell indices; microscopic urinalysis; newborn screening (this could also be done in nonneonates) and/or measurement of thyroid-stimulating hormone concentration; and examination for congenital anomalies (including fetal alcohol syndrome) should be considered as part of the initial evaluation of any immigrant child.*

Children should be examined within 1 month of arrival in the United States, or earlier if there are immediate health concerns, but foreign-born parents may not access the healthcare system with their children unless prompted by illness, school vaccination, or other legal requirements. *It is important to assess the completeness of previous medical screenings at any first visit with a foreign-born child.*

Clinicians should be aware of potential diseases in high-risk immigrant children and their clinical manifestations. Some diseases, such as central nervous system cysticercosis, may have incubation periods as long as several years and thus may not be detected during initial screening. On the basis of findings at the initial evaluation, consideration should be given to a repeat evaluation 6 months after arrival. In most cases, the longer the interval from arrival to development of a clinical syndrome, the less likely the syndrome can be attributed to a pathogen acquired in the country of origin.

Table 11.1 Infectious Disease Screening for Refugee Children

CONDITION OR TEST	REFUGEE CHILDREN
HEPATITIS A VIRUS (ACUTE INFECTION)	
Hepatitis A IgM antibody	Not recommended
HEPATITIS B VIRUS	
Hepatitis B surface antigen (HBsAg)	All
Hepatitis B surface antibody (anti-HBs)	All
Hepatitis B core antibody (anti-HBc)	All
HEPATITIS C VIRUS	
Hepatitis C antibody	Some
SYPHILIS	
Nontreponemal test (RPR, VDRL, or ART)	≥15 yr
Treponemal test (TPPA, MHA-TP, or FTA-ABS)	Not recommended
HUMAN IMMUNODEFICIENCY VIRUS	
Human immunodeficiency virus 1 and 2 antibody	≥13 yr
Recommended	<13 yr
TUBERCULOSIS	
Tuberculin skin test (TST)	All
or	
Interferon-γ release assay	≥2 yr
INTESTINAL PARASITES	
Microscopic evaluation of stool for ova and parasites	All (two specimens)*
Giardia intestinalis and *Cryptosporidium* antigen	All (one specimen)*
BACTERIAL ENTERIC INFECTION	
In children with diarrhea: bacterial stool culture	All
CHAGAS (ENDEMIC AREAS)	
Trypanosoma cruzi serologic testing	All
Complete blood count	All
EOSINOPHILIA WITH NEGATIVE STOOL OVA AND PARASITE FOR HELMINTHS	
Strongyloides serologic testing	All
Schistosoma serologic testing (endemic countries)*	
LYMPHATIC FILARIASIS (ENDEMIC AREAS)	
Filaria serology	All
CHAGAS (ENDEMIC AREAS)W	
Trypanosoma cruzi serologic testing	All
MALARIA SCREENING (ENDEMIC AREAS)	
Malaria polymerase chain reaction	All without pretreatment
HEMATURIA (SCHISTOSOMIASIS)	
Urinalysis	All

*Some experts recommend serologic testing regardless of whether eosinophilia is present.

ART, Automated reagin test; FTA-ABS, fluorescent treponemal antibody absorption; MHA-TP, microhemagglutination–*Treponema pallidum;* RPR, rapid plasma reagin; TPPA, *Treponema pallidum* particle agglutination; VDRL, Venereal Disease Research Laboratory.

Modified from Staat MA. Infectious disease considerations in international adoptees and refugees. In: Cherry JD, Harrison GJ, Kaplan SL, et al. (eds): *Feigin and Cherry's Textbook of Pediatric Infectious Diseases*. 8th ed. Philadelphia: Elsevier; 2019: Table 233.1, p. 2310.

* For the most up-to-date guidelines based on country of origin/birth, see: https://www.cdc.gov/immigrantrefugeehealth/guidelines/domestic/domestic-guidelines.html.

Table 11.2 Incubation Periods of Common Travel-Related Infections*

SHORT INCUBATION (<10 DAYS)	MEDIUM INCUBATION (10-21 DAYS)	LONG INCUBATION (>21 DAYS)
Malaria	Malaria	Malaria
Arboviruses including dengue, yellow fever, Japanese encephalitis, Zika, chikungunya	Flaviviruses: tick-borne encephalitis and Japanese encephalitis	Schistosomiasis
Hemorrhagic fevers: Lassa, Ebola, South American arenaviruses	Hemorrhagic fevers: Lassa, Ebola, Crimean-Congo	Tuberculosis
Respiratory viruses including severe acute respiratory syndrome	Acute HIV infection	Acute HIV infection
Typhoid and paratyphoid	Typhoid and paratyphoid	Viral hepatitis
Bacterial enteritis	*Giardia*	Filariasis
Rickettsia: spotted fever group—Rocky Mountain spotted fever, African tick typhus, Mediterranean spotted fever, scrub typhus, Q fever	*Rickettsia*: flea-borne, louse-borne, and scrub typhus, Q fever, spotted fevers (rare)	*Rickettsia:* Q fever
Bacterial pneumonia including *Legionella*	Cytomegalovirus	Secondary syphilis
Relapsing fever	*Toxoplasma*	Epstein-Barr virus including mononucleosis
Amoebic dysentery	Amoebic dysentery	Amoebic liver disease
Meningococcemia	Histoplasmosis	Leishmaniasis
Brucella (rarely)	*Brucella*	*Brucella*
Leptospirosis	Leptospirosis	Bartonellosis (chronic)
Fascioliasis	Babesiosis	Babesiosis
Rabies (rarely)	Rabies	Rabies
African trypanosomiasis (acute), East African (rarely)	East African trypanosomiasis (acute)	West African trypanosomiasis (chronic)
	Hepatitis A (rarely)	Cytomegalovirus
	Measles	

*Diseases that commonly have variable incubation periods are shown more than once. However, most diseases may rarely have an atypical incubation period, and this is not shown here.

HIV, Human immunodeficiency virus.

From Freedman DO. Infections in returning travelers. In: Bennett JE, Blaser MJ, Dolin R, et al (eds): *Mandell, Douglas, and Bennett's Principles and Practice of Infectious Diseases*, 8th ed. Philadelphia: Saunders;2015: Table 324-2.

COMMONLY ENCOUNTERED INFECTIONS

Hepatitis B

See also Chapter 406.

The prevalence of hepatitis B surface antigen (HBsAg) in refugee children ranges from 4% to 14%, depending on the country of origin, age, and year studied. Prevalence of markers of past hepatitis B virus (HBV) infection is higher. HBV infection is most prevalent in immigrants from Asia, Africa, and some countries in Central and Eastern Europe, as well as the former Soviet Union (e.g., Bulgaria, Romania, Russia, Ukraine), but also occurs in immigrants born in other countries. All immigrant children, even if previously vaccinated, coming from high-risk countries (HBsAg seropositivity >2%) should undergo serologic testing for HBV infection, including both HBsAg and antibody to HBsAg (anti-HBs), to identify current or chronic infection, past resolved infection, or evidence of previous immunization. Because HBV has a long incubation period (6 weeks to 6 months), the child may have become infected at or near the time of migration, and initial testing might be falsely negative. Therefore strong consideration should be given to a repeated evaluation 6 months after arrival for all children, especially those from highly endemic countries. Chronic HBV infection is indicated by persistence of HBsAg for >6 months. Children with HBsAg-positive test results should be evaluated to identify the presence of chronic HBV infection, which occurs in >90% of infants infected at birth or in the first year of life and in 30% of children exposed at ages 1-5 years. Once identified as being infected, additional testing should be done to assess for biochemical evidence of severe or chronic liver disease or liver cancer.

Hepatitis A

See Chapter 406.

Hepatitis C

See also Chapter 406.

The decision to screen children should depend on history (e.g., receipt of blood products; traditional percutaneous procedures such as tattooing, body piercing, circumcisions, or other exposures to reused, unsterile medical devices) and the prevalence of hepatitis C virus (HCV) infection in the child's country of origin. Children from Eastern Mediterranean and Western Pacific countries, Africa, China, and Southeast Asia should be considered for HCV infection screening. All children coming from Egypt, which has the highest known HCV seroprevalence (12% nationally and 40% in some villages), should be tested for hepatitis C.

Intestinal Pathogens

Fecal examinations for ova and parasites (O&P) by an experienced laboratory will identify a pathogen in 8–86% of immigrants and refugees. The prevalence of intestinal parasites varies by country of origin, time period when studied, previous living conditions (including water quality, sanitation, and access to footwear), and age, with toddler/young school-aged children being the most affected. If documented predeparture treatment was given, an eosinophil count should be performed. An absolute eosinophil count of >400 cells/μL, if persistently elevated for 3-6 months after arrival, should prompt further investigation for tissue-invasive parasites such as *Strongyloides* (see Chapter 341) and *Schistosoma* (see Chapter 346) species (if no predeparture ivermectin or praziquantel was given). If no documented predeparture treatment was given and screening eosinophils are >400 cells/μL, two stool O&P specimens obtained from separate morning stools should be examined by the concentration method *or* empiric ivermectin and praziquantel given. If the child is symptomatic, including evidence of poor physical growth, but no eosinophilia is present, a single stool specimen should also be sent for *Giardia lamblia* (see Chapter 328.1) and *Cryptosporidium parvum* (see Chapter 329) antigen detection. All potentially pathogenic parasites found should be treated appropriately. All nonpregnant refugees >2 years of age coming from sub-Saharan Africa and Southeast Asia should be presumptively treated with predeparture albendazole.

Tuberculosis

See also Chapter 261.

Tuberculosis (TB) commonly is encountered in immigrants from all countries because *Mycobacterium tuberculosis* infects approximately 30% of the world's population. Latent TB infection rates can be up to 60% in populations of refugee children from some regions of North Africa and the Middle East. Since 2007, TB *Technical Instructions for Medical Evaluation of Aliens* have required that children ages 2-14 years undergo a TB skin test or interferon-γ release assay if they are medically screened

in countries where the TB rate is ≥20 cases per 100,000 population. If the testing is positive, a chest radiograph is required. If the chest film suggests TB, cultures and three sputum smears are required, all before arrival in the United States. Check with the Centers for Disease Control and Prevention, Division of Global Migration and Quarantine, for the latest information (www.cdc.gov/ncidod/dq/technica.htm).

Congenital Syphilis

See Chapter 264.

HIV Infection

See Chapter 322.

IMMUNIZATIONS

See Chapter 215.

Immigrant children and adolescents should receive immunizations according to the recommended schedules in the United States for healthy children and adolescents. Some immigrants will have written documentation of immunizations received in their birth or home country. Although immunizations such as bacille Calmette-Guérin (BCG), diphtheria and tetanus toxoids and pertussis (DTP), poliovirus, measles, and HBV vaccines often are documented, other immunizations, such as *Haemophilus influenzae* type b, mumps, and rubella vaccines, are given less frequently, and *Streptococcus pneumoniae,* human papillomavirus, meningococcal, and varicella vaccines are given rarely. When doubt exists, an equally acceptable alternative is to reimmunize the child. Because the rate of more serious local reactions after DTP vaccine increases with the number of doses administered, serologic testing for antibody to tetanus and diphtheria toxins before reimmunizing, or if a serious reaction occurs, can decrease risk.

In children older than 6 months with or without written documentation of immunization, testing for antibodies to diphtheria and tetanus toxoid may be considered to determine whether the child has protective antibody concentrations. If the child has protective concentrations, the immunization series should be completed as appropriate for that child's age. In children older than 12 months, measles, mumps, rubella, and varicella antibody concentrations may be measured to determine whether the child is immune; these antibody tests should not be performed in children younger than 12 months because of the potential presence of maternal antibody.

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Chapter 12

Cultural Issues in Pediatric Care

Lee M. Pachter and Alexandra M.S. Corley

Pediatricians live and work in a multicultural world. Among the world's nearly 8 billion people residing in over 200 countries, more than 6,000 languages are spoken. As the global population becomes more mobile, population diversity increases in all countries. In the United States, sources of ethnic and cultural diversity come from indigenous groups, such as Indigenous Nation peoples and Alaskan and Hawaiian natives, groups from U.S. territories such as Puerto Rico, recent immigrant groups, those whose heritage originates from the African diaspora and arrived to U.S. soil forcibly via the middle passage of the transatlantic slave trade, and others whose families and communities migrated to the United States from Europe and Asia generations ago but who have retained cultural identification. U.S. census estimates suggest that in 2020, nearly 40% of the U.S. population self-identified as belonging to an ethnic group other than non-Hispanic white. Immigrants comprise 15.4% of the U.S. population. Based on recent estimates, 25% of children in the United States are either new immigrants or first-generation US citizens. Immigrants from China and India account for the largest groups coming to the United States, followed by those from Mexico and Latin America. This national and international diversity allows for a heterogeneity of experience that enriches the lives of everyone. Much of this diversity is based on varied cultural orientation.

WHAT IS CULTURE?

The concept of *culture* does not refer exclusively to ethnic categorizations. A common definition of **cultural group** is *a collective that shares common heritage, worldviews, beliefs, values, attitudes, behaviors, practices, and identity*. Cultural groups can be based on identities such as gender (cis, trans, nonbinary), sexual orientation (gay, lesbian, straight, bisexual), age (teen culture), being deaf or hearing impaired (deaf culture; see Chapter 55), and having neurodevelopmental differences (neurodiversity). Those who identify in such groups, to a certain extent, may share common worldviews, attitudes, beliefs, values, practices, and identities with others in the group.

As a part of their shared experiences, many cultural groups face oppression, which can affect their health. Therefore these cultural groups require focused consideration from healthcare providers, and we must critically examine societal factors like racism, sexism, ableism, and other forms of discrimination at the structural (institutional), interpersonal, and psychologic levels as root causes of health disparities (see Chapters 2 and 2.1). These premises are particularly relevant in a white supremacy and hegemony-based society such as the United States and previously colonized nations.

Medical professionals can also be considered as belonging to a specific cultural group. Those who identify with the **culture of medicine** share common theories of well-being and disease, acceptance of the biomedical and biopsychosocial models of health, and common practices and rituals. As with other cultural groups, physicians and other healthcare professionals have a distinct language and share a common history, including experiencing similar preparatory courses that must be mastered for entrance into training for the profession (a rite of passage) and a degree of socioeconomic privilege. Medical professionals subscribe to common norms in medical practice. Young physicians learn a way to describe health and illness that requires a new common vocabulary and an accepted structure for communicating a patient's history. These common beliefs, orientations, and practices are often not shared by those outside of medicine. Therefore *any clinical interaction between a healthcare provider and a patient can be a potential cross-cultural interaction*—between the culture of medicine and the culture of the patient—regardless of the ethnicity or socioeconomic status of the participants. A culturally informed and sensitized approach to clinical communication is a fundamental skill required of *all* medical professionals, regardless of the demographic makeup of one's patient population.

Culture, Identity, and Intersectionality

We are all members of multiple cultural groups. Our identification with different groups can be dynamic. How we identify may depend on the context in which we find ourselves and may change over time. A gay Latino physician may feel, at different times and in different situations, greatest affinity with Latino culture, the culture of medicine, the "minority" culture in the United States, or his gay identity. An immigrant from India may initially feel great connection with her Indian culture and heritage, which may wane during periods of assimilation into American cultural life, then increase again at other points in life. Alternatively, there may be identities that are not as flexible; a dark-skinned person will never be able to "pass" as White. An obese person will not have the "thin privilege" of their underweight counterpart. In addition, multiple cultural identities can intersect. **Intersectionality** is a concept that expresses the *interconnected nature of the different social categorizations an individual may be connected to and how those identities interact to create systems*

of disadvantage and/or privilege. Considering intersectionality helps to understand how people who are members of multiple disenfranchised groups may experience harm as a result of either identity or both simultaneously. For example, a Black woman's experience with navigating both racism and sexism might differ from how her White female colleague deals with sexism alone. Culturally informed clinicians should never assume to understand the cultural identity or experiences of a person based solely on their perception of ethnic, racial, or group affiliation.

Intracultural Variability

There can be significantly different beliefs, values, and behaviors among members of the same cultural group. There is as much variability *within* cultures as there is *between* cultures. The sources of this variability include differences in personal psychology and philosophy, family beliefs and practices, social context, and other demographic differences, as well as **acculturation**, defined as the changes in beliefs and practices resulting from continuous interactions with another culture. The literature on acculturation and health outcomes shows varied effects of cultural change on health and well-being. These differences are in part caused by overly simplistic ways of measuring acculturation in public health and health services research. The use of *acculturation proxies* such as generational status (recent immigration, first generation) and socioeconomic status as measures of acculturation do not allow for an understanding of the complex behavioral changes that occur during shifts in cultural orientation. Often, acculturation is seen as a linear process where individuals move from unacculturated to acculturated or assimilated into the host culture. This simplistic view does not consider the reality that acculturation is *multidimensional* and includes the degree to which an individual continues to identify with her original culture-of-origin identity, the degree to which the host cultural orientation is adopted, and how inviting and welcoming the host culture is. These are separate and independent processes (Fig. 12.1). One can become *bicultural* (adopting the host culture while retaining aspects of the original culture), *assimilated* (host culture is adopted, but original culture is not retained), *separated* (original cultural orientation is retained, but host culture is not greatly adopted), or *marginalized* (does not adopt host culture and does not retain original culture). These variations in the acculturation process are determined not only by the individual going through the cultural change process but also by the degree of acceptance of diversity in the host culture. In theory, individuals who best adapt to the multicultural society are those who are **bicultural** because they retain the strengths and assets of their heritage culture while being able to positively adjust to host cultural norms. However, historically and in the present day, people from various cultural groups have taken on acculturation in a variety of ways for different reasons (e.g., survival, safety, wealth attainment). The acculturative process can be a source of stress and may have a negative impact on health and contribute to health disparities. It is worth noting that the acculturation process is one that the majority culture often has little awareness of or participation in. Members of the majority culture should strive for cultural awareness as a foundation for a culturally informed practice.

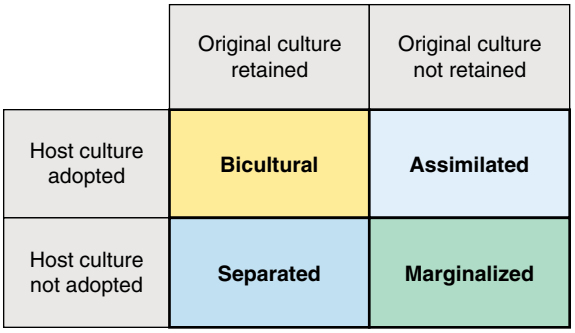

Fig. 12.1 Multidimensional model of acculturation. *(Adapted from Berry J. Immigration, acculturation, and adaptation. Appl Psychol 1997;46:5–68.)*

CULTURALLY INFORMED CARE

Physicians and patients bring to their interactions diverse orientations from multiple cultural systems. These different belief systems and practices could have significant implications for the delivery of healthcare and the receipt of health information. Consequently, physician cultural awareness, sensitivity, and humility are critical to successful patient-provider interaction.

The culturally informed physician (1) attempts to understand and respect the beliefs, values, attitudes, and lifestyles of all patients; (2) understands that health and illness are influenced by beliefs and practices originating from cultural orientation, linguistic considerations, religious and spiritual beliefs, and other socially constructed affiliations; (3) has insight into their own cultural biases and does not see cultural issues as something that only affects the patient; (4) is sensitive to how differences in power and privilege may affect the quality of the clinical encounter; (5) recognizes that in addition to the physiologic aspects of disease, the culturally and psychologically constructed meaning of illness and health is a central clinical issue; and (6) is sensitive to the role of intersectionality and intragroup variations in beliefs and practices and avoids stereotyping based on group affiliation. These core components of culturally informed care are important for interactions with *all* patients, regardless of socioeconomic status or ethnicity.

Becoming culturally informed is a developmental process. Figure 12.2 displays a framework that includes a continuum of perceptions and orientations to cultural awareness. Individuals in the *denial* stage perceive their own cultural orientation as the true one, with other cultures either undifferentiated or unnoticed. In the *defensive* stage, other cultures are acknowledged but regarded as inferior to one's own culture. The *minimization* stage is characterized by beliefs that fundamental similarities among people outweigh any differences and downplays the role of culture as a source of human variation. The mistaken idea that one should be "color blind" is an example of a common belief of individuals in the minimization stage and ignores the important historical adverse sociopolitical events faced by Black or other minoritized peoples.

As one moves to the *acceptance* stage, cultural differences are acknowledged. Further expansion and understanding lead to *adaptation,* where one not only acknowledges differences but can shift frames of reference and have a level of comfort outside one's own cultural frame. This eventually leads to further comfort with different worldviews seen at the *integration* stage, where individuals respect cultural differences and can comfortably interact across cultures with humility and respect.

Understanding Culture in the Context of Healthcare

Cultural orientation is just one of many different perspectives that individuals draw on as they make health and healthcare decisions. Individual psychology, past experiences (including racism), religious and spiritual views, social position, socioeconomic status (poverty), and family norms all can contribute to a person's health beliefs and practices as well as trust in the healthcare system.

Trust is essential to the patient–healthcare provider relationship. However, because of historical or current experiences, many cultures do not trust the healthcare system. In the past, Black people have been subjected to involuntary sterilization and not being treated for syphilis (the notorious Tuskegee study). Currently, Black people have received unequal pain relief and have experienced episodes of implicit and explicit racism in our healthcare system. These experiences create mistrust.

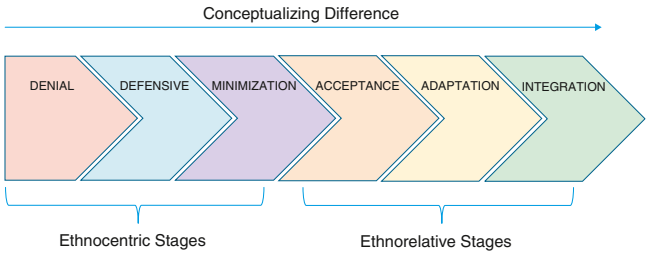

Fig. 12.2 Development of intercultural awareness. *(Adapted from Bennett MJ. A developmental approach to training for intercultural sensitivity. Int J Intercultural Relations. 1986;10:179–196.)*

The concept of intersectionality also contributes to the variability of beliefs and practices any individual subscribes to. These beliefs and practices can also change over time and may be expressed differently in different situations and circumstances. Because of the significant variability in health beliefs and behaviors seen among members of the same cultural group, an approach to cultural competency that emphasizes a "knowledge set" of specific cultural health practices in different cultural groups could lead to false assumptions and stereotyping. Knowledge is important, but it only goes so far. *Instead, an approach that focuses on the healthcare provider acquiring skills and attitudes relating to open and effective communication is a preferable approach to culturally effective and informed care.* Such an approach does not rely on rote knowledge of facts that may be stereotypical or outdated. Instead, it provides a toolbox that can be used in all circumstances. The following skills can lead to a culturally informed approach to care:

1. *Don't assume.* Presupposing that a particular patient may have certain beliefs or may act in a particular way based on stereotypic cultural group affiliation could lead to incorrect assumptions. Sources of intracultural diversity are varied. Multiple cultural identities can intersect and can contribute to a diversity of experiences.
2. *Practice humility.* Cultural humility has been described as "the ability to maintain an interpersonal stance that is 'other'-oriented (or open to the other) in relation to aspects of cultural identity." Cultural humility goes beyond cultural competency in that it requires the clinician to self-reflect and acknowledge that one's own cultural orientation enters any transaction with a patient.
   Cultural humility aims to address power imbalances between the dominant (hospital-medical) privileged culture and the patient. It incorporates the patient's life experiences. It creates a collaborative partnership between practitioner and patient. It also pushes the provider to critically examine their own biases and presuppositions.
   Cultural competency is an approach that typically focuses on the patient's culture, whereas cultural humility acknowledges that both physicians and patients have cultural orientations and that a successful relationship requires give and take among those differing perspectives. Cultural humility also includes an understanding that differences in social power, which are inherent in the physician-patient relationship, need to be understood and addressed so that open communication can occur.
3. *Understand and address privilege.* Members of the majority culture have certain privileges and benefits that are often unrecognized and unacknowledged. For example, they are more likely to be positively represented in media such as movies and television. Compared with minoritized groups, those in the majority culture have less chance of being followed by security guards at stores, stopped by the police, or having their bags checked. They have a greater chance of having a positive reception in a new neighborhood or of finding food in the supermarket that is consistent with their heritage. They have a lower likelihood of having to deal with the burden of racism and the acculturation process. These privileges typically go unnoticed by members of the majority culture, but their absence is painfully recognized by members of oppressed cultural groups. The culturally informed physician should try to be mindful of these privileges and power differentials and how they may influence their interactions with patients. Addressing such privilege might involve proactively centering traditionally silenced voices.
4. *Be inquisitive.* Because of the significant amount of intracultural diversity of beliefs and practices noted earlier, the only way to know a particular patient's approach to health and illness is through direct and effective communication. Asking about the patient's/family's perspective in an inquisitive and respectful manner will usually be met with open and honest responses, as long as the patient does not feel looked down on and the questions are asked in genuine interest. Obtaining a **health beliefs history** on *all* patients is an effective way of understanding clinical issues from the patient's and family's perspective (Table 12.1). The health beliefs history gathers information on the patient's views on the identification of health problems, causes, susceptibility, signs and symptoms, concerns, treatment, and expectations. Responses gathered from the health beliefs history can be helpful in guiding care plans and health education interventions.

Table 12.1 The Health Beliefs History

- What do you think is wrong with your child?
- Why do you think your child has gotten it (the illness)?
- What do you think caused it?
- Why do you think it started when it did?
- What do you think is happening inside the body?
- What are the symptoms that make you know your child has this illness?
- What problems does this illness cause your child?
- What are you most worried about with this illness?
- How long do you think it will last?
- How do you treat it?
- What will happen if it is not treated?
- What do you expect from the treatments?

Data from Kleinman A, Eisenberg L, Good B. Culture, illness and care: Clinical lessons from anthropologic and cross-cultural research. *Ann Intern Med.* 1978;88:251–258.

5. *Be flexible.* As members of the culture of medicine, clinicians have been educated and acculturated to the biomedical model as the optimal approach to health and illness. Patients and families may have health beliefs and practices that do not fully fit the biomedical model. Traditional beliefs and practices may be used in tandem with biomedical approaches without posing harm. An individual's approach to health rarely is exclusively biomedical or traditional and is often a combination of multiple approaches. The health beliefs history provides clinicians with information regarding nonbiomedical beliefs and practices that may be held by the patient. Culturally informed physicians should be flexible and find ways of integrating nonharmful traditional beliefs and practices into the medical care plan to make that plan fit the patient's needs and worldview, while still reaching the desired health outcome. This will likely result in better adherence to treatment and prevention.
   Obtaining a health beliefs history for a child with asthma, for example, may reveal that the family uses an **alternative remedy** when the symptoms first occur. If the symptoms do not resolve after giving the remedy, the family administers standard medical care. In this case, if the alternative remedy is safe and has no significant likelihood of causing adverse effects, the culturally informed physician might say, "I'm not sure if the remedy you're using is helpful or not, but I can say that if used as you described, it's not likely to be harmful. So, if you think it may work, feel free to try it. But instead of waiting to give the prescription medicine until after you see if the remedy works, why don't you give it at the same time you give the remedy? Maybe they'll work well together." This approach shows respect for the family-held beliefs and practices while increasing timely adherence to the biomedical therapy.

At times, an alternative therapy may be contraindicated or may have adverse effects. In this case it is advisable to recommend against the therapy, but whenever possible, one should attempt to replace the therapy with another, safer, culturally acceptable treatment. If a parent is giving a child tea containing harmful ingredients to treat a cold, the culturally informed physician could recommend stopping the practice and explain the concerns, but then recommend replacing the harmful tea with something safer that fits the family's cultural belief system, such as an herbal tea with no harmful ingredients. This requires an awareness and background knowledge of the cultural belief system, and this approach increases the chances that the family will follow through on the recommendation and feel that their beliefs are respected.

Awareness-Assessment-Negotiation Model

Providing care in the multicultural context can be challenging, but it offers opportunities for creativity and can result in improved long-term physician-patient relationships, which will ultimately improve the quality and outcomes of healthcare. Culturally informed care combines knowledge with effective communication skills, an open attitude, and the qualities of flexibility and humility.

The culturally informed physician should first become **aware** of common health beliefs, practices, and communication styles

of patients in the practice. Reading literature on particular groups could increase awareness, but with the caution that such information may be biased, outdated, or not specific to the local context. The best approach to becoming aware of specific health beliefs and practices is to ask—enter into conversations with patients, families, and community members. One might say, "Other families have shared with me that there are ways of treating this illness [or staying healthy] that work for them, but doctors do not know about them. Sometimes they are recommended by grandparents or others in the community. They may be effective. Have you heard of any of these?" This approach shows genuine interest and openness, is not based on presumptions, and does not ask about behaviors or practices, only if the patient has heard of these practices. If the question elicits a positive response, the conversation can then continue, including asking whether the patient has personally tried any of the therapies, under what circumstances, and if they thought it was helpful. This approach shows respect for the patient as an individual and avoids stereotyping all members of a particular group as monolithic in their cultural beliefs and practices.

The information obtained should be seen only as common ways that members of a community *may* interpret health-related issues. Assuming that all members subscribe to similar beliefs and practices would be incorrect and potentially damaging by promoting stereotypes. Because the unit of measurement in clinical care is the individual patient and family, clinicians must **assess** to what extent a specific patient may act on these general beliefs and under what circumstances. The health beliefs history can help the physician become aware of the specific beliefs and practices that a patient holds and allow one to tailor the care to the individual patient.

Once the patient's explanatory model is elicited and understood, the clinician should be able to assess the congruity of this model and the biomedical model, finding similarities. Then the process of **negotiating** can occur. Integrating patient-held approaches to health with evidence-based biomedical standards of care will help place care within the lifestyle and worldview of patients, leading to increased adherence to medical care plans, better physician-patient communication, enhanced long-term therapeutic relationships, better health outcomes, and improved patient (and physician) satisfaction. When there is a needed behavioral change, counseling for a patient or family should follow motivational interviewing best practices (see Chapter 18).

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Chapter 13

Maximizing Children's Health: Screening, Anticipatory Guidance, and Counseling

Joseph F. Hagan Jr. and Dipesh Navsaria

Health supervision visits from birth to age 21 are the platform for a young person's healthcare. Routine, scheduled care of well infants, children, and adolescents is an essential prevention effort for children and youth worldwide. The provision of **well care** in the medical home fosters strong relationships between the clinic or practice and the child and family, enabling the provision of appropriate surveillance, screening, and sick care.

To ensure the optimal health of the developing child, pediatric care in the United States and other countries evolved into regularly scheduled visits to ensure adequate nutrition, to detect and immunize against infectious diseases, and to observe the child's development. To foster optimal child healthy development, it is also wise to assess the child's or adolescent's emotional-behavioral health, their parents' mental health, their relational health, and their social determinants of health.

Well-child care focuses on the health and well-being of the child, but as children live in families of many varieties, it must also address that context by evaluating the needs, strengths, opportunities, and challenges of the identified family, including parents and other adults. Answering parents' questions while creating an environment where parents feel comfortable asking is an important feature of the well-child visit. Promoting family-centered care and partnership with parents increases the ability to elicit parental concerns, especially about their child's development, learning, behavior, and social needs. Addressing of needs may be as straightforward as supportive listening, or may include validation, and referral to an appropriate resource whether in the community or the adult's own medical home. Such two-generation approaches benefit both the parent and the child.

Ever-present and lying just beneath the surface of arguably of every pediatric encounter is the phenomenon of *relational health*. What is the health of the relationships within the family unit? Is the child surrounded by safe, stable, nurturing relationships? Or are they subject to unbuffered threats to their well-being? Are caregivers confident of their caregiving abilities? Do they have the capacity to do it well? This assessment followed by efforts to bolster relational health within families will act as a strong support to child development that has significant implications for the life course.

Contemporary analysis of changes in the population's health, coupled with the recognition that early life experiences and social factors affect health along the entire life course, call for a supportive environment providing positive childhood experiences that enhance the trajectory for child development and health. But stressful circumstances impair development, and **adverse childhood experiences** (ACEs) early in life increase the risk of disease (see Chapter 1). Adults who experienced abuse, violence, or other stressors as children have an increased risk for depression, heart disease, and other morbidities. Biology informs us that **ubuffered stress** leads to increased heart rate and blood pressure and increased levels of inflammatory cytokines, cortisol, and other stress hormones, all of which impair brain activity, immune status, and cardiovascular function. These impacts of stress present causal models of how ACEs, including those that could have been prevented, increase health risk and negatively affect the life course.

Preventive care for children, youth, and families offers great opportunity for health cost savings as a component of contemporary U.S. health reform activities. A thriving society and economy requires educated and healthy citizens and workers. For children to have a successful, meaningful, and useful educational experience, they must have physical, cognitive, and emotional health. Educational success in particular is tied to early childhood developmental competence. Well-child care plays a vital role in promoting adult health, a concept endorsed by business leaders as essential to building the human infrastructure of the U.S. economy and society.

THE PERIODICITY SCHEDULE AND GUIDELINES

The frequency and content for well-child care activities are derived from evidence-based practice and research. In addition, federal agencies and professional organizations, such as the American Academy of Pediatrics (AAP), have developed evidence-informed, expert consensus guidelines for care. The *Recommendations for Preventive Pediatric Health Care,* or **Periodicity Schedule**, is a compilation of

recommendations listed by age-based visits (Fig. 13.1). It is intended to guide practitioners of pediatric primary care to perform certain services and intentionally make observations at age-specific visits; it designates the standard for *preventive services* for U.S. children and youth and is referred to as such in some legislation. It is updated annually and is available online.

Comprehensive guides for care of well infants, children, and adolescents have been developed based on the Periodicity Schedule to expand and further recommend how practitioners might accomplish the tasks outlined. The current guideline standard is *The Bright Futures Guidelines for Health Supervision of Infants, Children, and Adolescents*, fourth edition (https://brightfutures.aap.org/Pages/default.aspx). These guidelines were developed by the AAP under the leadership of the Maternal Child Health Bureau of the U.S. Department of Health and Human Services, in collaboration with the National Association of Pediatric Nurse Practitioners, American Academy of Family Physicians, American Medical Association, American Academy of Pediatric Dentistry, Family Voices, and others.

TASKS OF WELL-CHILD CARE

The well-child encounter aims to promote the physical and emotional well-being of children and youth. Child health professionals, including pediatricians, family medicine physicians, nurse practitioners, and physician assistants, take advantage of the opportunity well-child visits provide to elicit parental questions and concerns, gather relevant family and individual health information, perform a physical examination, and initiate screening tests. The tasks of each well-child visit include the following:

1. Disease detection
2. Disease prevention
3. Health promotion
4. Anticipatory guidance

To achieve these outcomes, healthcare professionals employ techniques to screen for disease—or for the risk of disease—and provide advice about healthy behaviors. These activities lead to the formulation of appropriate anticipatory guidance and health advice.

Clinical detection of disease in the well-child encounter is accomplished by a careful physical examination and both surveillance and screening. In well-child care, **surveillance** occurs in every health encounter and is enhanced by repeated visits and observations with advancing developmental stages. It relies on the experience of a skilled clinician performing intentional observation over time facilitated and informed by the observations offered by parents. **Screening** is a more formal process using a validated assessment tool that has known sensitivity and specificity. For example, anemia *surveillance* is accomplished through taking a dietary history and seeking signs of anemia in the physical examination. Anemia *screening* is done by hematocrit or hemoglobin tests. Developmental *surveillance* relies on the observations of parents and the assessment of clinicians in pediatric healthcare who are knowledgeable about child development. Table 13.1 shows the age at which 75% or more of children would be expected to achieve a developmental milestone across multiple streams of development. Developmental *screening* involves trained personnel scoring and interpreting a structured developmental screening tool completed by parents (see Chapter 28).

The second essential action of the well-child encounter, **disease prevention**, may include both *primary prevention* activities applied to a whole population and *secondary prevention* activities aimed at patients with specific risk factors. For example, counseling about reducing fat intake is appropriate for all children and families. However, counseling is intensified for overweight and obese youth or in the presence of a family history of hyperlipidemia and its sequelae. The child and adolescent healthcare professional needs to individualize disease prevention strategies to the specific patient, family, and community.

Health promotion and **anticipatory guidance** activities distinguish the well-child health supervision visit from all other encounters with the healthcare system. Disease detection and disease prevention activities are germane to all interactions of children with physicians and other healthcare clinicians, but health promotion and anticipatory guidance shift the focus to wellness and to the strengths of the family (e.g., what is being done well and how this might be improved). This approach is an opportunity to help the family address relationship issues; broach important safety topics; access needed services; and engage with extended family, school, neighborhood, and community and spiritual organizations. This is a prime area for relational health to be conceptually housed in the mind of the skilled clinician.

It is not possible to cover all the topics suggested by comprehensive guidelines such as *Bright Futures* in the average 18-minute well-child visit. Child health professionals must prioritize the most important topics to cover. Consideration should be given to a discussion of the following:

- First and foremost, the agenda the parent or child brings to the health supervision visit.
- The topics where evidence suggests counseling is effective in behavioral change.
- The topics where there is a clear rationale for the issue's critical importance to health, such as sleep environment to prevent sudden unexpected infant death (SUID) or attention to diet and physical activity.
- A summary of the child's progress in emotional, cognitive, and social development; physical growth; and strengths.
- Issues that address the questions, concerns, or specific health problems relevant to the individual family.
- Community-specific problems that could significantly affect the child's health (e.g., neighborhood violence from which children need protection or the absence of bike paths that would promote activity).

INFANCY AND EARLY CHILDHOOD

Nutrition, physical activity, sleep, safety, and emotional, social, and physical growth, along with parental well-being, are critical for all children. For each well-child visit, there are topics specific to individual children based on their age, family situation, chronic health condition, or a parental concern, such as sleep environment to prevent SUID, activities to promote healthy weight, and fences around swimming pools. Attention should also be focused on the family milieu and other social determinants of health, including screening for parental depression (especially maternal postpartum depression) and other mental illness, family violence, substance abuse, nutritional inadequacy, and lack of housing. It is equally important to identify, acknowledge, and empower family strengths. These issues are essential to the care of young children.

Evidence-based approaches such as early literacy assessment and promotion (e.g., Reach Out and Read) provide a structure for enquiry, surveillance, and parent coaching efficiently within the health supervision visit.

It is important to identify children with developmental disorders as early as possible. Developmental surveillance at every visit combined with a structured developmental screening, neuromuscular screening, and autism screening at certain visits enhances early diagnosis, especially for mild to moderate delays or autism spectrum disorders for which early intervention is believed to be associated with reduced morbidity.

MIDDLE CHILDHOOD AND ADOLESCENCE

As the child enters school-age years, additional considerations emerge. Attention to their developing autonomy requires fostering a clinician-patient relationship that begins to separate from the clinician–child-family relationship, with increasing needs for privacy and confidentiality as the child ages. As gender awareness develops, supportive and nonjudgmental care that is inclusive of the array of gender identities and sexual orientations found in youth is essential, particularly for LGBTQ+ youth.

The six health behaviors that most significantly affect adolescent and adult morbidity and mortality are inadequate physical activity, poor nutrition, sexuality-related behaviors, substance use and abuse (including tobacco and vaporized nicotine), unintentional injury–related behaviors, and intentional injury–related behaviors. New morbidities related to social media affect all contemporary youth, starting at remarkably young ages. Children are particularly

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN®

Recommendations for Preventive Pediatric Health Care

Bright Futures/American Academy of Pediatrics

Bright Futures
prevention and health promotion for infants, children, adolescents, and their families™

Each child and family is unique; therefore, these Recommendations for Preventive Pediatric Health Care are designed for the care of children who are receiving nurturing parenting, have no manifestations of any important health problems, and are growing and developing in a satisfactory fashion. Developmental, psychosocial, and chronic disease issues for children and adolescents may require more frequent counseling and treatment visits separate from preventive care visits. Additional visits also may become necessary if circumstances suggest concerns.

These recommendations represent a consensus by the American Academy of Pediatrics (AAP) and Bright Futures. The AAP continues to emphasize the great importance of continuity of care in comprehensive health supervision and the need to avoid fragmentation of care.

Refer to the specific guidance by age as listed in the *Bright Futures Guidelines* (Hagan JF, Shaw JS, Duncan PM, eds. *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents.* 4th ed. American Academy of Pediatrics; 2017).

The recommendations in this statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

The Bright Futures/American Academy of Pediatrics Recommendations for Preventive Pediatric Health Care are updated annually.

	INFANCY								EARLY CHILDHOOD							MIDDLE CHILDHOOD						ADOLESCENCE										
AGE[1]	Prenatal[2]	Newborn[3]	3-5 d[4]	By 1 mo	2 mo	4 mo	6 mo	9 mo	12 mo	15 mo	18 mo	24 mo	30 mo	3 y	4 y	5 y	6 y	7 y	8 y	9 y	10 y	11 y	12 y	13 y	14 y	15 y	16 y	17 y	18 y	19 y	20 y	21 y
HISTORY Initial/Interval	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
MEASUREMENTS																																
Length/Height and Weight		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Head Circumference		●	●	●	●	●	●	●	●	●	●	●																				
Weight for Length		●	●	●	●	●	●	●	●	●	●																					
Body Mass Index[5]												●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Blood Pressure[6]		★	★	★	★	★	★	★	★	★	★	★	★	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
SENSORY SCREENING																																
Vision[7]		★	★	★	★	★	★	★	★	★	★	★	★	●	●	●	●	★	●	★	●	★	●	★	★	●	★	★	★	★	★	★
Hearing		●[8]	●[9] →	→	→	★	★	★	★	★	★	★	★	★	●	●	●	★	●	★	●	←	←	●[10] →	→	←	←	● →	←	←	● →	→	→
DEVELOPMENTAL/SOCIAL/BEHAVIORAL/ MENTAL HEALTH																																
Maternal Depression Screening[11]				●	●	●	●																									
Developmental Screening[12]								●			●		●																			
Autism Spectrum Disorder Screening[13]											●	●																				
Developmental Surveillance		●	●	●	●	●	●		●	●		●		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Behavioral/Social/Emotional Screening[14]		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Tobacco, Alcohol, or Drug Use Assessment[15]																						★	★	★	★	★	★	★	★	★	★	★
Depression and Suicide Risk Screening[16]																							●	●	●	●	●	●	●	●	●	●
PHYSICAL EXAMINATION[17]		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
PROCEDURES[18]																																
Newborn Blood		●[19]	●[20] →	→																												
Newborn Bilirubin[21]		●																														
Critical Congenital Heart Defect[22]		●																														
Immunization[23]		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Anemia[24]						★			●	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★
Lead[25]							★	★	● or ★[26]		★	● or ★[26]		★	★	★	★															
Tuberculosis[27]				★			★		★			★		★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★
Dyslipidemia[28]												★			★		★		★	←	● →	★	★	★	★	★	←	←	←	● →	→	→
Sexually Transmitted Infections[29]																						★	★	★	★	★	★	★	★	★	★	★
HIV[30]																						★	★	★	★	● →	→	→	→	→	→	→
Hepatitis B Virus Infection[31]		★ →	→	→	→	→	→	→	→	→	→	→	→	→	→	→	→	→	→	→	→	→	→	→	→	→	→	→	→	→	→	→
Hepatitis C Virus Infection[32]																													● →	→	→	→
Sudden Cardiac Arrest/Death[33]																						★ →	→	→	→	→	→	→	→	→	→	→
Cervical Dysplasia[34]																																●
ORAL HEALTH[35]							●[36]	●[36]	★		★	★	★	★	★	★	★															
Fluoride Varnish[37]							←	←	←	←	●	←	←	←	← →																	
Fluoride Supplementation[38]							★	★	★		★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★				
ANTICIPATORY GUIDANCE	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●

KEY: ● = to be performed ★ = risk assessment to be performed with appropriate action to follow, if positive ←★ or ●→ = range during which a service may be provided

Fig. 13.1 Recommendations for preventive pediatric healthcare. The AAP updates the *Periodicity Schedule* annually. The current *Periodicity Schedule* should be consulted at https://downloads.aap.org/AAP/PDF/periodicity_schedule.pdf. (*From Bright Futures/American Academy of Pediatrics. Copyright 2022, American Academy of Pediatrics. Elk Grove Village, IL.* https://www.aap.org/en-us/documents/periodicity_schedule.pdf.)

1. If a child comes under care for the first time at any point on the schedule, or if any items are not accomplished at the suggested age, the schedule should be brought up to date at the earliest possible time.
2. A prenatal visit is recommended for parents who are at high risk, for first-time parents, and for those who request a conference. The prenatal visit should include anticipatory guidance, pertinent medical history, and a discussion of benefits of breastfeeding and planned method of feeding, per "The Prenatal Visit" (https://doi.org/10.1542/peds.2018-1218).
3. Newborns should have an evaluation after birth, and breastfeeding should be encouraged (and instruction and support should be offered).
4. Newborns should have an evaluation within 3 to 5 days of birth and within 48 to 72 hours after discharge from the hospital to include evaluation for feeding and jaundice. Breastfeeding newborns should receive formal breastfeeding evaluation, and their mothers should receive encouragement and instruction, as recommended in "Breastfeeding and the Use of Human Milk" (https://doi.org/10.1542/peds.2011-3552). Newborns discharged less than 48 hours after delivery must be examined within 48 hours of discharge, per "Hospital Stay for Healthy Term Newborn Infants" (https://doi.org/10.1542/peds.2015-0699).
5. Screen, per "Expert Committee Recommendations Regarding the Prevention, Assessment, and Treatment of Child and Adolescent Overweight and Obesity: Summary Report" (https://doi.org/10.1542/peds.2007-2329C).
6. Screening should occur per "Clinical Practice Guideline for Screening and Management of High Blood Pressure in Children and Adolescents" (https://doi.org/10.1542/peds.2017-1904). Blood pressure measurement in infants and children with specific risk conditions should be performed at visits before age 3 years.
7. A visual acuity screen is recommended at ages 4 and 5 years, as well as in cooperative 3-year-olds. Instrument-based screening may be used to assess risk at ages 12 and 24 months, in addition to the well visits at 3 through 5 years of age. See "Visual System Assessment in Infants, Children, and Young Adults by Pediatricians" (https://doi.org/10.1542/peds.2015-3596) and "Procedures for the Evaluation of the Visual System by Pediatricians" (https://doi.org/10.1542/peds.2015-3597).
8. Confirm initial screen was completed, verify results, and follow up, as appropriate. Newborns should be screened, per "Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs" (https://doi.org/10.1542/peds.2007-2333).
9. Verify results as soon as possible, and follow up, as appropriate.
10. Screen with audiometry including 6,000 and 8,000 Hz high frequencies once between 11 and 14 years, once between 15 and 17 years, and once between 18 and 21 years. See "The Sensitivity of Adolescent Hearing Screens Significantly Improves by Adding High Frequencies" (https://www.sciencedirect.com/science/article/abs/pii/S1054139X16000483).
11. Screening should occur per "Incorporating Recognition and Management of Perinatal Depression Into Pediatric Practice" (https://doi.org/10.1542/peds.2018-3259).
12. Screening should occur per "Promoting Optimal Development: Identifying Infants and Young Children With Developmental Disorders Through Developmental Surveillance and Screening" (https://doi.org/10.1542/peds.2019-3449).
13. Screening should occur per "Identification, Evaluation, and Management of Children With Autism Spectrum Disorder" (https://doi.org/10.1542/peds.2019-3447).
14. Screen for behavioral and social-emotional problems per "Promoting Optimal Development: Screening for Behavioral and Emotional Problems" (https://doi.org/10.1542/peds.2014-3716), "Mental Health Competencies for Pediatric Practice" (https://doi.org/10.1542/peds.2019-2757), "Clinical Practice Guideline for the Assessment and Treatment of Children and Adolescents With Anxiety Disorders" (https://pubmed.ncbi.nlm.nih.gov/32439401), and "Screening for Anxiety in Adolescent and Adult Women: A Recommendation From the Women's Preventive Services Initiative" (https://pubmed.ncbi.nlm.nih.gov/32510990). The screening should be family centered and may include asking about caregiver emotional and mental health concerns and social determinants of health, racism, poverty, and relational health. See "Poverty and Child Health in the United States" (https://doi.org/10.1542/peds.2016-0339), "The Impact of Racism on Child and Adolescent Health" (https://doi.org/10.1542/peds.2019-1765), and "Preventing Childhood Toxic Stress: Partnering With Families and Communities to Promote Relational Health" (https://doi.org/10.1542/peds.2021-052582).
15. A recommended assessment tool is available at http://crafft.org.
16. Screen adolescents for depression and suicide risk, making every effort to preserve confidentiality of the adolescent. See "Guidelines for Adolescent Depression in Primary Care (GLAD-PC): Part I. Practice Preparation, Identification, Assessment, and Initial Management" (https://doi.org/10.1542/peds.2017-4081), "Mental Health Competencies for Pediatric Practice" (https://doi.org/10.1542/peds.2019-2757), "Suicide and Suicide Attempts in Adolescents" (https://doi.org/10.1542/peds.2016-1420), and "The 21st Century Cures Act & Adolescent Confidentiality" (https://www.adolescenthealth.org/Advocacy/Advocacy-Activities/2019-(1)/NASPAG-SAHM-Statement.aspx).
17. At each visit, age-appropriate physical examination is essential, with infant totally unclothed and older children undressed and suitably draped. See "Use of Chaperones During the Physical Examination of the Pediatric Patient" (https://doi.org/10.1542/peds.2011-0322).
18. These may be modified, depending on entry point into schedule and individual need.
19. Confirm initial screen was accomplished, verify results, and follow up, as appropriate. The Recommended Uniform Screening Panel (https://www.hrsa.gov/advisory-committees/heritable-disorders/rusp/index.html), as determined by The Secretary's Advisory Committee on Heritable Disorders in Newborns and Children, and state newborn screening laws/regulations (https://www.babysfirsttest.org/) establish the criteria for and coverage of newborn screening procedures and programs.
20. Verify results as soon as possible, and follow up, as appropriate.
21. Confirm initial screening was accomplished, verify results, and follow up, as appropriate. See "Hyperbilirubinemia in the Newborn Infant ≥35 Weeks' Gestation: An Update With Clarifications" (https://doi.org/10.1542/peds.2009-0329).
22. Screening for critical congenital heart disease using pulse oximetry should be performed in newborns, after 24 hours of age, before discharge from the hospital, per "Endorsement of Health and Human Services Recommendation for Pulse Oximetry Screening for Critical Congenital Heart Disease" (https://doi.org/10.1542/peds.2011-3211).
23. Schedules, per the AAP Committee on Infectious Diseases, are available at https://publications.aap.org/redbook/pages/immunization-schedules. Every visit should be an opportunity to update and complete a child's immunizations.
24. Perform risk assessment or screening, as appropriate, per recommendations in the current edition of the AAP *Pediatric Nutrition: Policy of the American Academy of Pediatrics* (Iron chapter).
25. For children at risk of lead exposure, see "Prevention of Childhood Lead Toxicity" (https://doi.org/10.1542/peds.2016-1493) and "Low Level Lead Exposure Harms Children: A Renewed Call for Primary Prevention" (https://www.cdc.gov/nceh/lead/docs/final_document_030712.pdf).
26. Perform risk assessments or screenings as appropriate, based on universal screening requirements for patients with Medicaid or in high prevalence areas.
27. Tuberculosis testing per recommendations of the AAP Committee on Infectious Diseases, published in the current edition of the AAP *Red Book: Report of the Committee on Infectious Diseases*. Testing should be performed on recognition of high-risk factors.
28. See "Integrated Guidelines for Cardiovascular Health and Risk Reduction in Children and Adolescents" (http://www.nhlbi.nih.gov/guidelines/cvd_ped/index.htm).
29. Adolescents should be screened for sexually transmitted infections (STIs) per recommendations in the current edition of the AAP *Red Book: Report of the Committee on Infectious Diseases*.
30. Screen adolescents for HIV at least once between the ages of 15 and 21, making every effort to preserve confidentiality of the adolescent, as per "Human Immunodeficiency Virus (HIV) Infection: Screening" (https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/human-immunodeficiency-virus-hiv-infection-screening); after initial screening, youth at increased risk of HIV infection should be retested annually or more frequently, as per "Adolescents and Young Adults: The Pediatrician's Role in HIV Testing and Pre- and Postexposure HIV Prophylaxis" (https://doi.org/10.1542/peds.2021-055207).
31. Perform a risk assessment for hepatitis B virus (HBV) infection according to recommendations per the USPSTF (https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/hepatitis-b-virus-infection-screening) and in the 2021–2024 edition of the AAP *Red Book: Report of the Committee on Infectious Diseases*, making every effort to preserve confidentiality of the patient.
32. All individuals should be screened for hepatitis C virus (HCV) infection according to the USPSTF (https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/hepatitis-c-screening) and Centers for Disease Control and Prevention (CDC) recommendations (https://www.cdc.gov/mmwr/volumes/69/rr/rr6902a1.htm) at least once between the ages of 18 and 79. Those at increased risk of HCV infection, including those who are persons with past or current injection drug use, should be tested for HCV infection and reassessed annually.
33. Perform a risk assessment, as appropriate, per "Sudden Death in the Young: Information for the Primary Care Provider" (https://doi.org/10.1542/peds.2021-052044).
34. See USPSTF recommendations (https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/cervical-cancer-screening). Indications for pelvic examinations prior to age 21are noted in "Gynecologic Examination for Adolescents in the Pediatric Office Setting" (https://doi.org/10.1542/peds.2010-1564).
35. Assess whether the child has a dental home. If no dental home is identified, perform a risk assessment (https://www.aap.org/en/patient-care/oral-health/oral-health-practice-tools/) and refer to a dental home. Recommend brushing with fluoride toothpaste in the proper dosage for age. See "Maintaining and Improving the Oral Health of Young Children" (https://doi.org/10.1542/peds.2014-2984).
36. Perform a risk assessment (https://www.aap.org/en/patient-care/oral-health/oral-health-practice-tools/). See "Maintaining and Improving the Oral Health of Young Children" (https://doi.org/10.1542/peds.2014-2984).
37. The USPSTF recommends that primary care clinicians apply fluoride varnish to the primary teeth of all infants and children starting at the age of primary tooth eruption (https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/prevention-of-dental-caries-in-children-younger-than-age-5-years-screening-and-interventions1). Once teeth are present, apply fluoride varnish to all children every 3 to 6 months in the primary care or dental office based on caries risk. Indications for fluoride use are noted in "Fluoride Use in Caries Prevention in the Primary Care Setting" (https://doi.org/10.1542/peds.2020-034637).
38. If primary water source is deficient in fluoride, consider oral fluoride supplementation. See "Fluoride Use in Caries Prevention in the Primary Care Setting" (https://doi.org/10.1542/peds.2020-034637).

Fig. 13.1 cont'd

Table 13.1 Developmental Milestones Across Streams of Development

AGE	STREAMS OF DEVELOPMENT			
	LANGUAGE	COGNITIVE	MOTOR	SOCIAL EMOTIONAL
2 mo	• Makes sounds other than crying • Reacts to loud sounds	• Watches you as you move • Looks at a toy for several seconds	• Holds head up when on tummy • Opens hands briefly	• Calms when spoken to or picked up • Looks at face • Seems happy to see parent • Smiles when parent talks to them
4 mo	• Makes cooing sounds • Makes sounds back when talked to • Turns head towards sound of parent's voice	• If hungry, opens mouth when sees breast or bottle • Looks at hands with interest	• Holds head steady without support when being held • Uses arms to swing at toys • Brings hands to mouth • Pushes up onto elbows/ forearms when on tummy	• Smiles to get parent's attention • Chuckles responsively • Attempts to get parent's attention using eye contact, movement, or sounds
6 mo	• Takes turns making sounds • Sticks tongue out and blows (e.g., raspberries) • Makes squealing noises	• Puts things in mouth to explore them • Reaches to grab a toy • Closes lips when does not want more food	• Rolls from tummy to back • Pushes up with straight arms when on tummy • Leans on hands for support when sitting	• Knows familiar people • Likes to look at self in a mirror • Laughs
9 mo	• Makes babbling sounds • Lifts arms up to be picked up	• Looks for objects when dropped out of sight • Bangs 2 things together	• Gets to a sitting position on one's own • Transfers things between hands • Uses fingers to "rake" food • Sits without support	• Is shy or clingy around strangers • Makes several facial expressions like happy, sad, angry, or surprised • Looks when you call name • Smiles or laughs when playing peek-a-boo
12 mo	• Waves "bye-bye" • Has name for parent such as "mama" or "dada" • Understands "no" (not just tone of voice)	• Puts something in a container, like a block in a cup • Looks for things they see you hide	• Pulls up to stand • Walks holding on to furniture • Drinks from a cup without a lid as parent holds it • Picks things up between thumb and pointer finger	• Plays games with parent, like pat-a-cake
15 mo	• Approximates saying 1 or 2 words besides "mama" or "dada" • Looks at a familiar object when named • Follows directions given with gesture • Points to request object or help (e.g., proto-imperative pointing)	• Tries to use things the right way, like a phone, cup, or book • Stacks at least 2 small objects, like blocks	• Takes a few steps on own • Able to finger feed	• Copies other children playing • Shows parent an object they like • Claps when excited • Hugs stuffed doll or other toy • Shows parent affection
18 mo	• Says 3 or more words besides "mama" or "dada" • Follows 1-step directions without a gesture • Points to show interest (e.g., proto-declarative pointing)	• Copies parent doing chores • Plays with toys in a simple way, like pushing a toy car	• Walks on own • Scribbles • Drinks from a cup without a lid, may spill sometimes • Tries to use a spoon • Climbs on and off a couch or chair without help	• Checks in when moving away from parent • Puts hands out to be washed • Looks at a book with parent • Helps with dressing by pushing arm through sleeve or lifting up foot
2 yr	• Points to pictures in book on request • Says at least 2 words together (e.g., more milk) • Points to 2 or more body parts on request • Uses more gestures than just waving and pointing (e.g., blowing a kiss, nodding yes)	• Holds something while using the other hand (e.g., holding container and taking lid off) • Tries to use knobs, switches, or buttons on toys • Plays with more than 1 toy at the same time (e.g., putting toy food on toy plate)	• Kicks a ball • Runs • Walks (not climbs) up a few stairs with or without help • Eats with a spoon	• Notices when others are hurt or upset, like pausing or looking sad when someone is crying • Looks at parent's face to see how to react in a new situation
2½ yr	• Says about 50 words • Says 2 or more words, with 1 action word (e.g., doggie run) • Names things in a book when you point and ask, "What is this?" • Says words like "I," "me," or "we"	• Engages in pretend play • Shows simple problem-solving skills (e.g., using a stool to reach something) • Follows 2-step instructions • Knows at least 1 color	• Uses hands to twist things (e.g., turning doorknobs or lids) • Takes off some clothes on own • Jumps off the ground with both feet • Turns book pages, 1 at a time, when read to	• Plays next to other children and at times with them • Shows what he or she can do by saying, "Look at me!" • Follows simple routines when told (e.g., clean-up time)

Table 13.1 Developmental Milestones Across Streams of Development—cont'd

AGE	STREAMS OF DEVELOPMENT			
3 yr	• Has conversation using at least 2 back-and-forth exchanges • Asks "who," "what," "where," or "why" questions • Says what action is happening in a picture or book (e.g., running, eating) • Says first name when asked • Talks well enough for others to understand most of the time	• Imitates drawing a circle • Avoids touching hot objects, like a stove, when warned	• Strings items together, like large beads or macaroni • Puts on some clothes on own • Uses a fork	• Calms down within 10 min after parent leaves (e.g., at childcare drop-off) • Notices other children and joins them to play
4 yr	• Says sentences with 4 or more words • Talks about at least 1 thing that happened during the day • Answers simple questions (e.g., what is a coat for?)	• Names a few colors • Tells what comes next in a well-known story • Draws a person with 3 or more body parts	• Catches a large ball most of the time • Serves themselves food or pours water, with adult supervision • Unbuttons some buttons • Holds crayon or pencil between fingers and thumb (not a fist)	• Pretends to be something else during play (e.g., teacher, dog) • Asks to play with children • Comforts others who are hurt or sad • Likes to be a "helper" • Changes behavior based on location (e.g., library, playground)
5 yr	• Tells a story they heard or made up with at least 2 events • Answers simple questions about a book or story • Keeps a conversation going with more than 3 back-and-forth exchanges • Uses or recognizes simple rhymes (e.g., bat-cat, ball-tall)	• Counts to 10 • Names some numbers between 1 and 5 when you point to them • Uses words about time, like yesterday, tomorrow, morning, or night • Pays attention for 5 to 10 min during activities • Writes some letters in name • Names some letters when they are pointed to	• Buttons some buttons • Hops on 1 foot	• Follows rules or takes turns when playing games with other children • Sings, dances, or acts • Does simple chores at home

Adapted from Centers for Disease Control Developmental Milestones: https://www.cdc.gov/ncbddd/actearly/milestones/index.html. Accessed March 19, 2022.

vulnerable to advertising of unhealthy products and behaviors because of immature skills in critical thinking and impulse control. Emotional well-being and early diagnosis and treatment of mental health problems are crucially important, with attention to the developmental tasks of adolescence: competence at school and other activities, connection to friends and family, autonomy, empathy, and a sense of self-worth.

Children and Youth with Special Healthcare Needs

This set of frameworks must be directed at *all children*, including children and youth with special healthcare needs (CYSHCN). CYSHCN are no different from other children in their need for guidance about healthy nutrition, physical activity, progress in school, connection with friends, a healthy sense of self-efficacy, and avoidance of risk-taking behaviors. The existence of frequent visits to the medical home or specialists to address the special health needs sometimes masks the lack of general health supervision care. The coordination of specialty consultation, medication monitoring, and functional assessment, which should occur in their periodic visits, needs to be balanced with a discussion of the child's unique ways of accomplishing the emotional, social, and developmental tasks of childhood and adolescence. Comprehensive, integrated care planning for CYSHCN should support partnerships between family-centered medical homes and families and youth through goal setting and negotiating next steps. In this process, chronic condition management and health surveillance (including adolescent engagement and planning for transition to adult care) occur within an effective patient care relationship, partnering to improve health outcomes and efficiencies of current and future care provision.

OFFICE INTERVENTION FOR BEHAVIORAL AND MENTAL HEALTH ISSUES

One fifth of primary care encounters with children are for a behavioral or mental health problem or sickness visits complicated by a mental health issue. Pediatricians and other primary care clinicians seeing children must have reasonable comfort with and knowledge for diagnosis, treatment, and referral criteria for attention-deficit/hyperactivity disorder (see Chapter 50), depression and other mood disorders (see Chapter 39), anxiety (see Chapter 38), and conduct disorder (see Chapter 42), as well as an understanding of the pharmacology of the frequently prescribed psychotropic medications. Familiarity with available local mental health services and clinicians and knowledge of the types of services indicated are important for effective consultation or referral. With new understanding of the impact of lifestyle on mood disorders and anxiety, encouragement of behavioral change to implement regular exercise, a healthy diet, avoidance of substances, and judicious use of media has become an important responsibility of the primary care clinician. **Motivational interviewing** (see Chapter 18) provides a structured approach that has been designed to help patients and parents identify the discrepancy between their desire for health and

the outcomes of their current behavioral choices. It also allows the clinician to use proven strategies that lead to a patient-initiated plan for change.

Strength-Based Approaches and Framework

Questions about school or extracurricular accomplishments or competent personal characteristics should be integrated into the content of the well child visit. Such inquiries set a positive context for the visit, deepen the partnership with the family, acknowledge the child's healthy development, and facilitate discussing social-emotional development with children and their parents. There is a strong relationship between appropriate social-emotional development (e.g., children's strong connection to their family, social friends, and mentors; competence; empathy; appropriate autonomy) and decreased participation in all the risk behaviors of adolescence (related to drugs, sex, and violence). An organized approach to the identification and encouragement of a child's strengths during health supervision visits provides both the child and the parent with an understanding of how to promote healthy achievement of the developmental tasks of childhood and adolescence. It also provides an opportunity to assess and comment on the relational health in the family. CYSHCN often have a different timetable, but they have an equal need to be encouraged to develop strong family and peer connections, competence in a variety of arenas, ways to do things for others, and appropriate independent decision-making.

Family Support Programs

Family support can range from the informal, to the highly formalized, to the referral to other agencies. Informal supports can be incorporated easily into existing assessment or anticipatory guidance. More formalized programs incorporate clinician and clinic staff training and guidance for the family while still operating within the existing framework of the well-child visit, such as Reach Out and Read. Even more structured are programs such as HealthySteps or Video Interaction Project, which address deeper needs for support through additional personnel and time. Finally, agencies external to the medical home, like evidence-based home visiting, can offer even greater intensity or flexibility of service.

This continuum of offerings allows a clinician to "tune" the intensity of services to meet the needs of a family while maintaining the support and connection of the medical home in the face of the reality of families who have needs far beyond what can be addressed immediately. Family support programs should be selected and offered based on available evidence and strong elements of reproducibility, scalability, and clarity. Advocacy for funding for family support programs is also imperative.

Office System Change for Quality Improvement

To facilitate the effective delivery of preventive services for children and youth, screening schedules and parent handouts, flow sheets, registries, and parent and youth previsit questionnaires are available in *The Bright Futures Guidelines Toolkit*. These efforts are part of a larger national effort that is built on a coordinated team approach in the office setting and the use of continuous measurement for improvement.

EVIDENCE

Available evidence should be used in developing health-promotion and disease-detection recommendations. Revisions to the AAP Periodicity Schedule undergo rigorous evidence assessment; however, many highly valued well-child care activities have not been evaluated for efficacy. Lack of evidence is most often related to absence of systematic study and does not necessarily mean lack of benefit. Thus the clinical encounter with the well child is also guideline and recommendation driven and requires the integration of clinician goals, family needs, and community realities in seeking better health for the child. The evidence and rationale for recommendations in the Periodicity Schedule (see Fig. 13.1) and *Bright Futures Guidelines* regarding well-child care activities are a balance of evidence from research, clinical practice guidelines, professional recommendations, expert opinion, experience, and knowledge of the needs of the patient population in the context of community assets and challenges. Clinical or counseling decisions and recommendations may also be based on local legislation (e.g., seat belts), on commonsense measures not likely to be studied experimentally (e.g., lowering water heater temperatures, use of car seats), or on the basis of relational evidence (e.g., television watching associated with violent behavior in young children). Most importantly, sound clinical and counseling decisions are responsive to family needs and desires and support patient-centered decision-making.

CARING FOR THE CHILD AND YOUTH IN THE CONTEXT OF THE FAMILY AND COMMUNITY

A successful primary care practice for children incorporates families, is family centered, and embraces the concept of the medical home. To be considered a **medical home**, a primary care practice must certify that their care is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective. In a medical home, a clinician works in partnership with the family and patient to ensure that all medical and nonmedical needs of the child are met. Through this partnership, the child healthcare professional helps the family/patient access and coordinate specialty care, educational services, out-of-home care, family support, and other public and private community services that are important to the overall health of the child and family.

Health promotion activities occur not only in the medical home but also through community members and other health and education professionals. To be most effective, communication and coordination around providing accurate, consistent information is key, with a clear understanding of the important role that the community plays in supporting healthy behaviors among families. Communities where children and families feel safe and valued and have access to positive activities and relationships provide the important base that the healthcare professional can build on and refer to for needed services that support health but are outside the realm of the healthcare system or primary care medical home. It is important for the medical home and community agencies to identify mutual resources, communicate well with families and each other, and partner in designing service delivery systems. This interaction is the practice of **community pediatrics**, whose unique feature is its concern for all the population: those who remain well but need preventive services, those who have symptoms but do not receive effective care, and those who do seek medical care in a physician's office or hospital.

Contemporary and future health supervision of children and adolescents must evolve to improve the delivery of this comprehensive care, which is critical to the healthy development of every child, their family, and their community. Relevant practice models for delivery of health supervision care will continue to evolve to provide comprehensive care and partnership with medical and community services to serve their patients and families. Such models will appropriately broaden the sphere of primary care pediatrics and foster partnerships in community care. Pediatric clinicians should also advocate not only for individual patients but also for system change for the betterment of this and future generations.

Health reform is key to this work to assure that an evidence-based, comprehensive system of health supervision is supported. Payment modalities might vary, but payment must recognize that the work of healthcare and the essential work of those providing preventive care to children is poorly recognized, supported, and remunerated by most existing payment systems. The success of accountable care organizations and any other current or future healthcare system can and should require strengthening and broadening primary care preventive services. This reform must acknowledge and embrace the already existing reality that preventive care is so much more than merely height, weight, and immunizations.

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Chapter 14

Injury Control

Brian D. Johnston and Sadiqa Kendi

In all high-income countries of the world, and increasingly in many low- and middle-income countries, injuries are the most common cause of death during childhood and adolescence beyond the first few months of life (Table 14.1 and Fig. 14.1). Injuries represent one of the most important causes of preventable pediatric morbidity and mortality in the United States. Identification of risk factors for injuries has led to the development of successful programs for prevention and control. Strategies for injury prevention and control should be pursued by the pediatrician in the office, emergency department (ED), hospital, and community setting.

Injuries have identifiable risk and protective factors that can be used to define prevention strategies. The term *accident* implies a chance event occurring without pattern or predictability. In fact, most injuries occur under predictable circumstances to children and families known to be at risk. *Most injuries are preventable.*

Reduction of morbidity and mortality from injuries can be accomplished not only through *primary* prevention (averting the event or injury) but also through *secondary* and *tertiary* prevention. The latter two approaches include appropriate **emergency medical services** (EMS) for injured children; **regionalized trauma care** for the child with multiple injuries, severe burns, or traumatic brain injury; and **specialized pediatric rehabilitation** services to optimize functional recovery after injury.

Injury control also encompasses *intentional injuries* (assaults and self-inflicted injuries). These injuries are important in adolescents and young adults, and in some populations, these rank first or second as causes of death in these age-groups. Many of the same principles of injury control can be applied to these problems; for example, limiting access to firearms may reduce unintentional shootings and also homicides and suicides.

SCOPE OF THE PROBLEM

Mortality

In the United States, injuries cause 41% of deaths among 1- to 4-year-old children and 3.2 times more deaths than the next leading cause, congenital anomalies. For the rest of childhood and adolescence up to age 19 years, 65% of deaths are a result of injuries, more than all other causes combined. In 2019, injuries caused 13,384 deaths (16.4 deaths per 100,000 population) among individuals ≤19 years old in the United States, resulting in more years of potential life lost than any other cause. **Unintentional injuries** remained the leading cause of death among those <24 years old in 2019 (see Table 14.1).

Motor vehicle injuries lead the list of injury deaths among school-age children and adolescents and are the second leading cause of injury death for those age 1-4 years. In children and adults, motor vehicle *occupant* injuries account for most of these deaths. During adolescence, occupant injuries are the leading cause of injury death, accounting for >50% of unintentional trauma mortality in this age-group.

Drowning ranks second overall as a cause of unintentional injury deaths among those age 1-19 years, with peaks in the preschool and later teenage years (see Chapter 88). In some areas of the United States, drowning is the leading cause of injury death for preschool-age children. The causes of drowning deaths vary with age and geographic area. In young children, bathtub and swimming pool drowning predominates, whereas in older children and adolescents, drowning occurs in natural bodies of water while swimming or boating.

Fire- and burn-related deaths account for 3% of all unintentional trauma deaths, with the highest rates among those <5 years of age (see Chapter 89). Most deaths are a result of house fires and are caused by smoke inhalation or asphyxiation rather than severe burns. Children and elderly persons are at greatest risk for these deaths when they cannot independently escape from burning buildings.

Suffocation represents approximately 87% of all unintentional deaths in children <1 year old. Some cases result from choking on food items, such as hot dogs, candy, grapes, and nuts. Nonfood items that can cause choking include undersized infant pacifiers, small balls, and latex balloons. An increasing number of infant suffocation deaths represent sleep-related mortality in the presence of unsafe bedding or crib bumpers, or when co-sleeping with an impaired adult. In previous years these might have been classified as sudden infant death syndrome (see Chapter 423).

Homicide is the third leading cause of injury death in children 1-4 years old and in adolescents (15-19 years old) (Fig. 14.2). Homicide in the pediatric age-group falls into two patterns: infant (child) and adolescent. Child homicide involves children <5 years old and represents child abuse (see Chapter 17). The perpetrator is usually a caretaker; death is generally the result of blunt trauma to the head and/or abdomen. The adolescent pattern of homicide involves peers and acquaintances and is caused by firearms in 77.6% of cases. The majority of these deaths involve handguns. Children between these two age-groups experience homicides of both types.

Suicide is rare in children <10 years old; however, the rate increases greatly after age 10 years, with the result that suicide is now the second leading cause of death for 10- to 19-year-olds. Approximately 50.6% of teenage suicides involve firearms (see Chapter 40).

There has been a sharp and substantial increase in unintentional **poisoning** deaths among teens and young adults. In 2019, unintentional poisonings were the second leading cause of injury deaths among 15- to 24-year-olds. Many of these were from prescription analgesic and opioid medications such as fentanyl.

Nonfatal Injuries

Most childhood injuries do not result in death. Approximately 12% of children and adolescents receive medical care for an injury each year in hospital EDs, and at least as many are treated in physicians' offices. Of these, 2% require inpatient care, and 55% have at least short-term disability because of their injuries.

The distribution of nonfatal injuries is very different from that of fatal trauma (Fig. 14.3). **Falls** are the leading cause of both ED visits and hospitalizations. **Bicycle-related trauma** is the most common type of sports and recreational injury, accounting for approximately 300,000 ED visits annually. **Nonfatal injuries** may be associated with severe morbidity such as anoxic encephalopathy from near-drowning, scarring and disfigurement from burns, and persistent neurologic deficits from head injury, leading to substantial changes in the quality of life for victims and their families. In 2010, nonfatal injuries to U.S. children <19 years old resulted in >$32 billion in direct medical and lifetime work-loss costs.

Global Child Injuries

Child injuries are a global public health issue, and prevention efforts are necessary in low-, middle-, and high-income countries. Between 1990 and 2010 there was a 53% decrease in mortality of people of all ages from communicable, maternal, neonatal, and nutritional disorders, whereas injury mortality decreased by only 16% (Fig. 14.4).

Worldwide, almost 1 million children and adolescents die from injuries and violence each year, and >90% of these deaths are in low- and middle-income countries. As child mortality undergoes an epidemiologic transition because of better control of infectious diseases and malnutrition, injury increasingly becomes a leading cause of death for children in the developing world, as it now is in all industrialized countries. Drowning is the fifth most common cause of death for 5- to 9-year-old children globally, and in some countries, such as Bangladesh, it is the leading cause of death among children 1-4 years old, with a rate over 50 times greater than that in the United States.

An estimated 1 billion people do not currently have immediate access to roads; as industrialization and motorization spread, the incidence of motor vehicle crashes, injuries, and fatalities will climb.

Table 14.1 Injury Deaths in the United States, 2019 (N [rate per 100,000])

CAUSE OF DEATH	<1 YEAR	1-4 YEARS	5-9 YEARS	10-14 YEARS	15-19 YEARS	0-19 YEARS
All causes	20,921 (553.0)	3,676 (23.3)	2,333 (11.6)	3,164 (15.2)	10,258 (48.7)	40,352 (49.4)
All injuries	1,645 (43.48)	1,494 (9.46)	915 (4.53)	1,536 (7.39)	7,794 (37.02)	13,384 (16.40)
All unintentional	1,266 (33.47)	1,149 (7.28)	714 (3.54)	778 (3.74)	3,537 (16.80)	7,444 (9.12)
Motor vehicle occupant	16 (0.42)	67 (0.42)	91 (0.45)	106 (0.51)	654 (3.11)	934 (1.14)
Pedestrian	7 (0.19)	158 (1.00)	78 (0.39)	94 (0.45)	225 (1.07)	562 (0.69)
Drowning	34 (0.90)	378 (2.39)	133 (0.66)	100 (0.48)	216 (1.03)	861 (1.05)
Fire and burn	8 (0.21)	76 (0.48)	71 (0.35)	40 (0.19)	35 (0.17)	230 (0.28)
Poisoning	14 (0.37)	27 (0.17)	12 (0.06)	21 (0.10)	692 (3.29)	766 (0.94)
Pedal cyclist	0 (0.00)	4 (0.03)	13 (0.06)	26 (0.13)	53 (0.25)	96 (0.12)
Firearm	2 (0.05)	24 (0.15)	9 (0.04)	16 (0.08)	66 (0.31)	117 (0.14)
Fall	7 (0.19)	23 (0.15)	14 (0.07)	14 (0.07)	55 (0.26)	113 (0.14)
Suffocation	1,095 (28.94)	139 (0.88)	33 (0.16)	28 (0.13)	40 (0.19)	1,335 (1.64)
All intentional	263 (6.95)	284 (1.80)	167 (0.83)	725 (3.49)	4,123 (19.58)	562 (6.81)
Suicide	0 (0.00)	0 (0.00)	12 (0.06)	534 (2.57)	2,210 (10.50)	2,756 (3.38)
Firearm suicide	*0 (0.00)*	*0 (0.00)*	*0 (0.00)*	*172 (0.83)*	*995 (4.73)*	*1,167 (1.43)*
Homicide	263 (6.95)	284 (1.80)	155 (0.77)	191 (0.92)	1,877 (8.91)	2,770 (3.39)
Firearm homicide	*10 (0.26)*	*47 (0.30)*	*68 (0.34)*	*144 (0.69)*	*1,754 (8.33)*	*2,023 (2.48)*
Undetermined intent	116 (3.07)	61 (0.39)	34 (0.17)	33 (0.16)	134 (0.64)	378 (0.46)

Injury data from Centers for Disease Control and Prevention (CDC): Web-based Injury Statistics Query and Reporting System (WISQARS) (website). National Center for Injury Prevention and Control, CDC (producer). https://www.cdc.gov/injury/wisqars/.
All cause mortality data from Centers for Disease Control and Prevention, National Center for Health Statistics.
Underlying Cause of Death 1999-2019 on CDC WONDER Online Database, released in 2020. Data are from the Multiple Cause of Death Files, 1999-2019, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. http://wonder.cdc.gov/ucd-icd10.html. Accessed June 4, 2021.

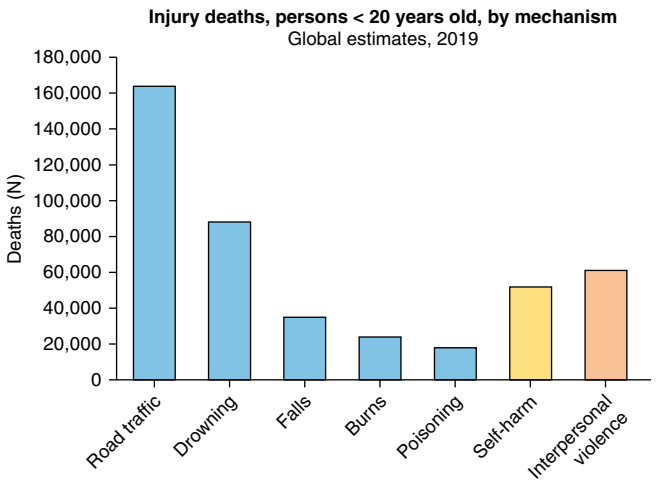

Fig. 14.1 Global injury deaths, persons <20 years old, by mechanism, in 2019. (*From Global Burden of Disease Collaborative Network, Global Burden of Disease Study 2019 [GBD 2019] Results. Seattle, United States: Institute for Health Metrics and Evaluation [IHME], 2020. Available from* http://ghdx.healthdata.org/gbd-results-tool.)

The rate of child injury death in low- and middle-income countries is threefold higher than that in high-income countries and reflects both a higher incidence of many types of injuries and a much higher case fatality rate in those injured because of a lack of access to emergency and surgical care. As in high-income countries, prevention of child injuries and consequent morbidity and mortality is feasible with multifaceted approaches, many of which are low cost and of proven effectiveness.

PRINCIPLES OF INJURY CONTROL

Injury prevention once centered on attempts to pinpoint the innate characteristics of a child that result in greater frequency of injury. Most now discount the theory of the "accident-prone child." For example, although longitudinal studies have demonstrated an association between attention-deficit/hyperactivity disorder (ADHD; see Chapter 50) and increased rates of injury, the sensitivity and specificity of these traits as a test to identify individuals at high risk for injury are extremely low. The concept of *accident proneness* is counterproductive in that it shifts attention away from more modifiable factors, such as product design or the built environment. It is more appropriate to examine the physical and social environment of children with frequent rates of injury than to try to identify personality traits or temperaments, which are difficult to modify.

Efforts to control injuries include education or persuasion, changes in product design, and modification of the social and physical environment. Efforts to persuade individuals, particularly parents, to change their behaviors have constituted the greater part of injury control efforts. Speaking with parents specifically about using child car seat restraints and bicycle helmets, installing smoke detectors, and checking the tap water temperature is likely to be more successful than offering well-meaning but too-general advice about supervising the child closely, being careful, and childproofing the home. This **information should be geared to the developmental stage of the child and presented in moderate doses in the form of anticipatory guidance** at well-child visits. Table 14.2 lists topics to discuss at each developmental

stage. It is important to acknowledge that there are many barriers to prevention adherence beyond simple knowledge acquisition; pediatricians should be familiar with low-cost sources for safety equipment such as bicycle helmets, smoke detectors, trigger locks, and car seats in their community.

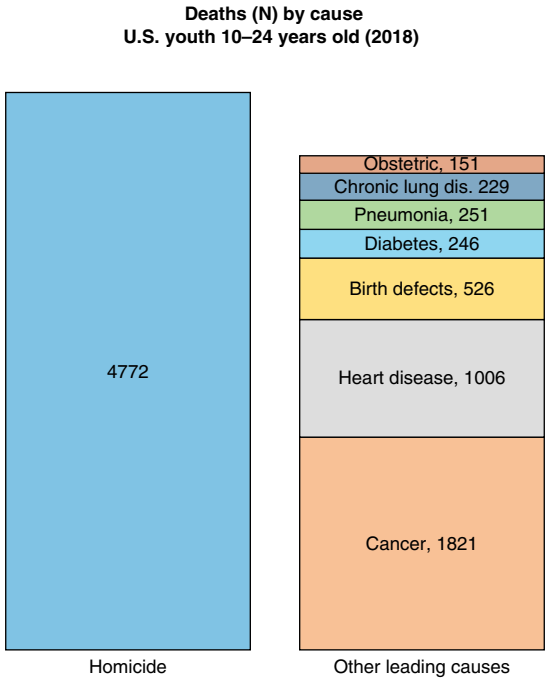

Fig. 14.2 Chart showing third leading cause of death (homicide) among persons aged 10-24 years compared with fourth through tenth leading causes of death in the same age-group in the United States in 2018. Does not include the two leading causes of death among persons aged 10-24 years in 2018: unintentional injuries (12,736 deaths) and suicide (6,807). (*Data from Centers for Disease Control and Prevention, National Center for Injury Prevention and Control.* (https://www.cdc.gov/injury/wisqars/LeadingCauses_images.html. *Accessed July 12, 2021.*)

The most successful injury prevention strategies generally are those involving **changes in product design**. These passive interventions protect all individuals in the population, regardless of cooperation or level of skill, and are likely to be more successful than measures that require repeated behavioral actions by the parent or child. The most important and effective product changes have been in motor vehicles, in which protection of the passenger compartment, use of airbags, and development of crash avoidance and driving support technologies have had large effects on injury risk. Reducing the factory-set water heater temperature, installing smoke detectors, and using child-resistant caps on medicines and household products are other examples of effective product modifications. Many interventions require both active and passive measures: smoke detectors provide passive protection when fully functional, but behavior change is required to ensure periodic battery changes and proper testing.

Modification of the environment often requires greater changes than individual product modification but may be very effective in reducing injuries. Safe roadway design, decreased traffic volume and speed limits in neighborhoods, and elimination or safe storage of guns in households are examples of such interventions. Included in this concept are changes in the social environment through legislation, such as laws mandating child seat restraint and seatbelt use, zero-tolerance laws for alcohol-impaired driving, and graduated driver's licensing laws.

Prevention campaigns combining two or more of these approaches have been particularly effective in reducing injuries. The classic example is the combination of legislation and education to increase child seat restraint and seatbelt use; other examples are programs to promote bike helmet use among school-aged children and improvements in occupant protection in motor vehicles.

RISK FACTORS FOR CHILDHOOD INJURIES

Major factors associated with an increased risk of injuries to children include age, sex, socioeconomic status, rural-urban location, and the environment.

Age

Infants are especially vulnerable to sleep-related suffocation and to abusive head trauma. Toddlers are at the greatest risk for burns, drowning, and falling. Poisonings become another risk as these

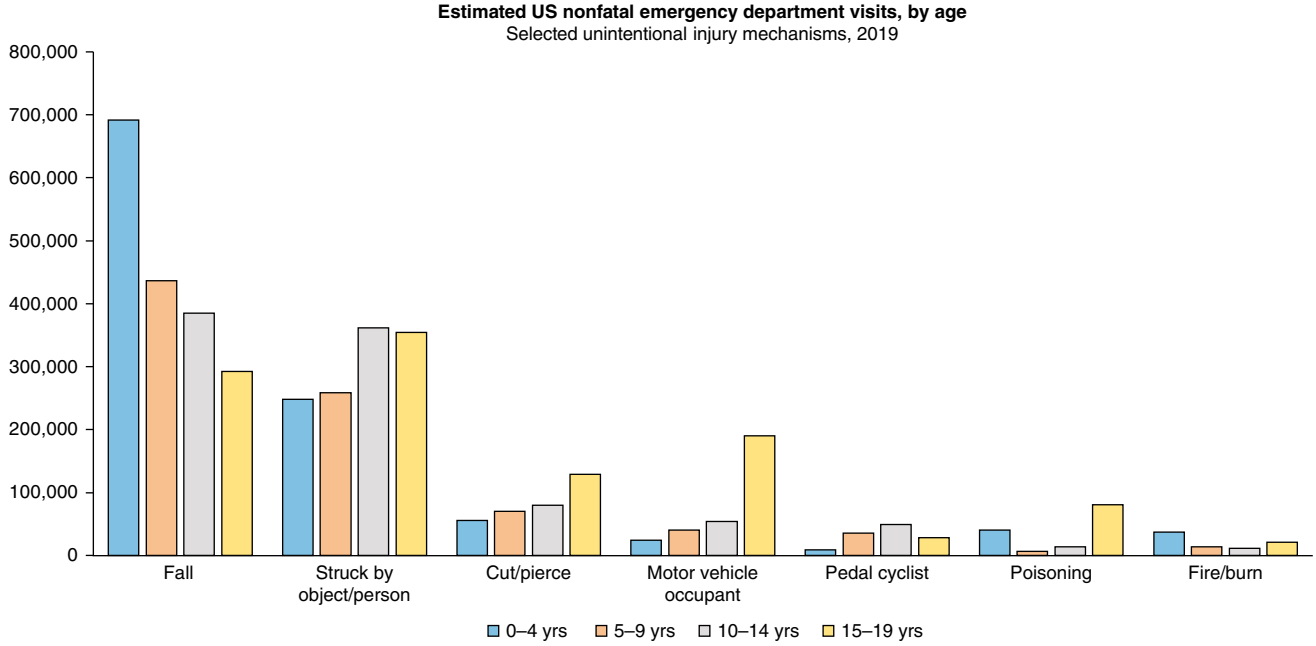

Fig. 14.3 Estimated U.S. nonfatal emergency department visits, by age for selected unintentional injury mechanisms, 2019. (*Injury data from Centers for Disease Control and Prevention [CDC]. Web-based Injury Statistics Query and Reporting System (WISQARS) (website); National Center for Injury Prevention and Control, CDC (producer).* https://www.cdc.gov/injury/wisqars/nonfatal.html. *Accessed July 12, 2021.*)

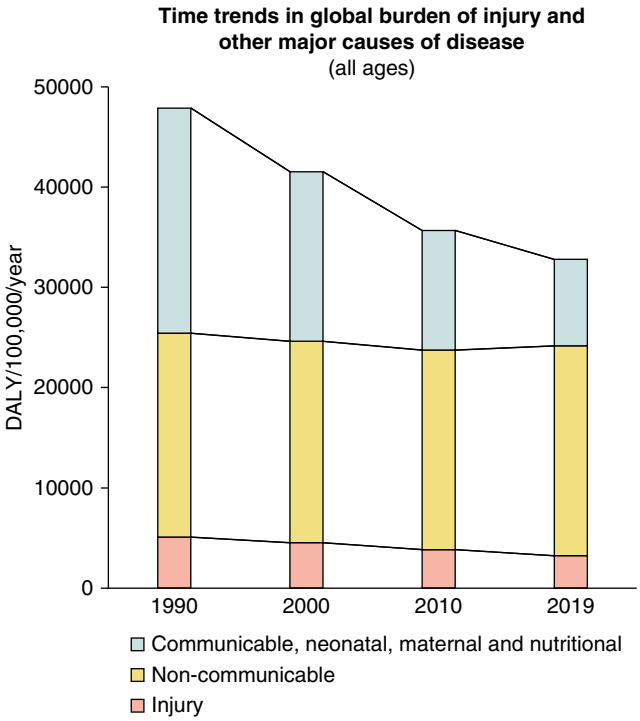

Fig. 14.4 Rates of disability-adjusted life-years (DALYs) lost per 100,000 per year by major grouping of cause. (*Data from Institute for Health Metrics and Evaluation; GBD data visualization site,* https://vizhub.healthdata.org/gbd-compare/. *Accessed July 14, 2021.*)

children acquire mobility and exploratory behavior. Young school-age children are at greatest risk for pedestrian injuries, bicycle-related injuries (the most serious of which usually involve motor vehicles), motor vehicle occupant injuries, burns, and drowning. During the teen years, there is a greatly increased risk from motor vehicle occupant trauma, a continued risk from drowning and burns, and the new risk of intentional trauma. Sports- and recreation-related injuries, including concussion, become more common, and more serious, as children age. Work-related injuries associated with child labor, especially for 14- to 16-year-olds, are an additional risk.

Injuries occurring at a particular age represent a period of vulnerability during which a child or an adolescent encounters a new task or hazard that they may not have developed the cognitive, socioemotional, or physical skills to handle successfully. Toddlers do not have the judgment to know that medications can be poisonous or that some houseplants are not to be eaten; they do not understand the hazard presented by a swimming pool or an open second-story window. For young children, parents may inadvertently set up this mismatch between the skills of the child and the demands of the task. Many parents expect young school-age children to walk home from school, the playground, or the local convenience store, tasks for which most children are not developmentally ready. Likewise, the lack of skills and experience to handle many tasks during the teenage years contributes to an increased risk of injuries, particularly motor vehicle injuries. The high rate of motor vehicle crashes among 15- to 17-year-olds is caused primarily by inexperience, but also reflects their level of cognitive development and emotional maturity. Alcohol, other drugs, and distraction from mobile phone use substantially add to these limitations.

Age also influences the severity of injury and the risk of long-term disability. Young school-age children have an incompletely developed pelvis. In a motor vehicle crash, a seatbelt does not anchor onto the pelvis but rides up onto the abdomen, resulting in the risk of serious abdominal injury. Proper restraint for 4- to 8-year-old children requires the use of booster seats. Children <2 years old have much poorer outcomes from traumatic brain injuries than older children and adolescents, partly related to the unique severity of abusive head trauma.

Table 14.2 Injury Prevention Topics for Anticipatory Guidance by the Pediatrician

NEWBORN
Car seats
Tap water temperature
Smoke detectors
Sleep safety
INFANT
Car seats
Tap water temperature
Bath safety
Choking prevention
TODDLER AND PRESCHOOLER
Car seats and booster seats
Water safety
Poison prevention
Fall prevention
PRIMARY SCHOOL CHILD
Pedestrian skills training
Water skills training
Booster seats and seat belts
Bicycle and sports helmets
Safe storage of firearms in the home
MIDDLE SCHOOL CHILD
Pedestrian skills training
Seatbelts
Safe storage of firearms in the home
Water skills training
Sports safety and concussion prevention
HIGH SCHOOL AND OLDER ADOLESCENT
Seatbelts
Alcohol and drug use, especially while driving and swimming
Driving risks and readiness
Safe storage of firearms
Sports safety and concussion prevention
Occupational injuries

Gender

Beginning at 1-2 years of age and continuing throughout the life span, males have higher rates of fatal injury than do females. During childhood, this does *not* appear to be primarily a result of developmental differences between the genders, differences in coordination, or differences in muscle strength. Variation in *exposure* to risk may account for the male predominance in some types of injuries. Although males in all age-groups have higher rates of bicycle-related injuries, adjusting for exposure reduces this excess risk. Gender differences in rates of pedestrian injuries do *not* appear to be caused by differences in the amount of walking but rather reflect differences in *behavior* between young females and males; whether these are genetic or the result of gender socialization is uncertain. Greater risk-taking behavior, combined with greater frequency of alcohol use, may lead to the disproportionately high rate of motor vehicle crashes among teenage males. The rate of violence-related injuries is higher among males because of their higher rates of aggression and risk-taking behaviors.

Socioeconomic Status

Poverty is one of the most important risk factors for childhood injury. Mortality from fires, motor vehicle crashes, and drowning is 2-4 times higher in poor children. Death rates have an inverse relationship to income level: the higher the income level, the lower the death rate. Many other identified injury risk factors, such as single-parent families,

teenage parents, multiple care providers, family stress, and having multiple siblings, are also mediated primarily through their strong association with poverty.

Rural-Urban Location

Injury rates are generally higher in rural than in urban areas. Homicide rates are higher in urban areas, as is violent crime in general. However, suicide among adolescents is higher in rural than in urban areas. Case fatality from injury is generally twice as high in rural areas than in urban areas, reflecting both the increased severity of some injuries (e.g., motor vehicle crashes occurring at higher speeds) and poorer access to EMS and definitive trauma care. Some injuries are unique to rural areas, such as agricultural injuries to children and adolescents.

Environment

Poverty increases the risk of injury to children at least in part through its effect on the environment. Children who are poor are at increased risk for injury because they are exposed to more hazards in their living environments. They may live in poor housing, which is more likely to be dilapidated and less likely to be protected by smoke detectors. The roads in their neighborhoods are more likely to be major thoroughfares. Their neighborhoods are more likely to experience higher levels of violence, and they are more likely to be victims of assault than children and adolescents living in the suburbs. The focus on the environment is also important because it directs attention away from relatively immutable factors, such as family dynamics, child temperament, and race and directs efforts toward factors that can be changed through interventions.

Ethnic Disparities

In the United States, Indigenous Nation children have the highest death rate from unintentional injuries, followed by Black, Hispanic, and White children. These discrepancies are even more pronounced for some injuries. The homicide rate for Black children aged 15-19 years was 34.86 per 100,000 population in 2019 compared with 7.67/100,000 for Indigenous Nations and Alaskan Natives and 3.86/100,000 for Whites and 2.72/100,000 for Asians. The suicide rate for Indigenous Nation youth was 2.1 times the rate for Whites and 3.2 times the rate for Blacks. Disparities in fatal drowning rates vary by age, with highest rates in the 1- to 4-year-old age group in Indigenous Nation and Alaskan Native children (4.1/100,000) and in the 5- to 9- and 10- to 14-year-old age-groups in Black children (1.5/100,000 and 1.6/100,000, respectively). Indigenous Nation teenagers 15-19 years old are at the highest risk for suicide, followed by White males; Black females have the lowest rate of suicide in this age-group.

It is important to acknowledge racial disparities in injury rates and recognize that the underlying risk factors are racism and social determinants of health (such as socioeconomic status, the educational status of parents, natural and built environment conditions, and access to timely high-quality trauma care), rather than race itself.

MECHANISMS OF INJURY

Motor Vehicle Injuries

Motor vehicle injuries are the leading cause of serious and fatal injuries for children and adolescents. Large and sustained reductions in motor vehicle crash injuries can be accomplished by identifiable interventions.

Occupants

Injuries to passenger vehicle occupants are the predominant cause of motor vehicle deaths among children and adolescents. The peak injury and death rate for both males and females in the pediatric age-group occurs between 15 and 19 years (see Table 14.1). Proper restraint use in vehicles is one of the most effective methods for preventing serious or fatal injury in children involved in motor vehicle crashes. Table 14.3 shows the recommended restraints at different ages. Figure 14.5 provides examples of car safety seats.

Much attention has been given to child occupants <8 years old. Use of child-restraint devices, infant car seats, and booster seats can be expected to reduce fatalities by 71% and the risk of serious injuries by 67% in this age-group. All 50 states and the District of Columbia have laws mandating their use, although the upper age limit for booster seat requirements varies by state. Physician reinforcement of the positive benefits of child seat restraints has been successful in improving parent acceptance.

Table 14.3 Recommended Child-Restraint Methods

	INFANTS	TODDLERS (1-3)	YOUNG CHILDREN
Recommended age/weight requirements	Birth to 1 yr or below weight limit of seat.	Older than 1 yr and weight 20-40 lb.	Weight 40-80 lb and height under 4 ft 9 in; generally, between 4 and 8 yr of age.
Type of seat	Infant-only or Rear-facing convertible.	Convertible or Forward-facing harness seat.	Forward-facing car seat with harness and tether until height or weight limit allowed by manufacturer. Then, belt-positioning booster seat.
Seat position	Rear-facing only. Place in back seat of vehicle.	Rear-facing as long as possible, until height or weight limit allowed by manufacturer. Then forward facing. Place in back seat of vehicle.	Forward-facing. Always in back seat of vehicle.
Notes	Children should use rear-facing seat until at least 1 yr and at least 20 lb. Harness straps should be at or below shoulder level.	Harness straps should be at or above shoulder level. Most seats require top strap for forward-facing use.	Belt-positioning booster seats must be used with both lap and shoulder belts. Make sure that lap belt fits low and tightly across lap/upper thigh area and that shoulder belt fits snugly, crossing chest and shoulder to avoid abdominal injuries.

Data from the National Highway Traffic Safety Administration, https://www.nhtsa.gov/equipment/car-seats-and-booster-seats.

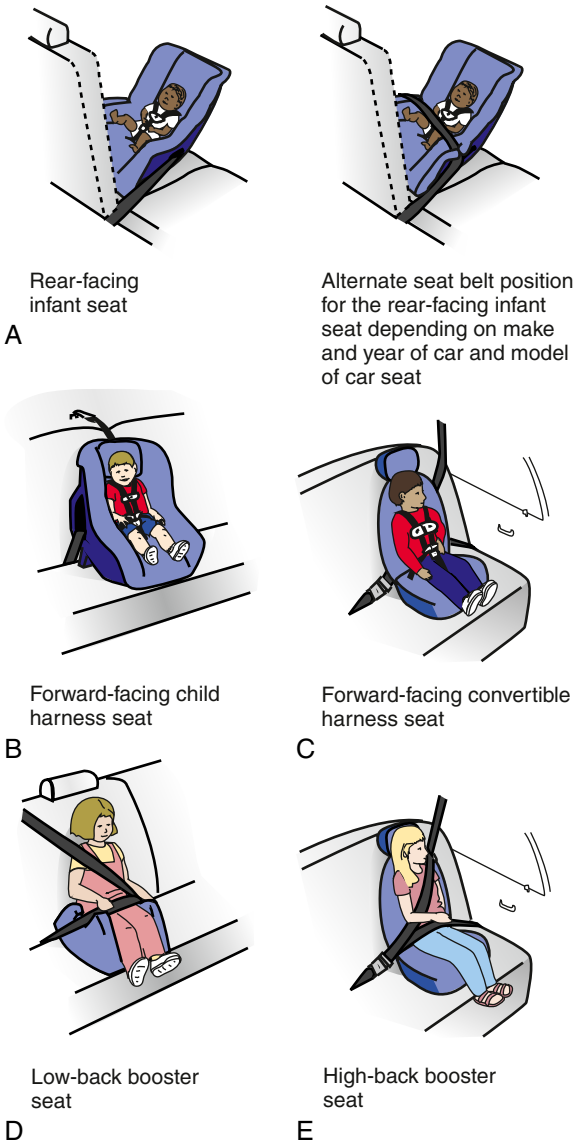

Fig. 14.5 Car safety seats. A, Rear-facing infant seat. B, Forward-facing child harness seat. C, Forward-facing convertible harness seat. D, Low-back booster seat. E, High-back booster seat. (*From Ebel BE, Grossman DC. Crash proof kids? An overview of current motor vehicle child occupant safety strategies. Curr Probl Pediatr Adolesc Health Care. 2003;33:33–64. Source: NHTSA.*)

A detailed guide and list of acceptable devices is available from the American Academy of Pediatrics (AAP)* and the National Highway Traffic Safety Administration (NHTSA).† Infants may use an infant seat within the height and weight guidelines of the seat or may be placed in a convertible infant-toddler child-restraint device. Infants and toddlers should remain rear facing until at least 2 years old and up to the weight and height limits of their seat. Once toddlers outgrow the rear-facing limits of their seat, they can be placed in a forward-facing child harness seat until it is outgrown. Emphasis must be placed on the correct use of these seats, including placing the seat in the right direction, routing the belt properly, and ensuring that the child is buckled into the rear seat of the car correctly. Government regulations specific to automobile and product design, including the Lower Anchors and Tethers for Children (LATCH) system, have made the fit between car seats and the car easier, quicker, and less prone to error.

Older children are often not adequately restrained. Many ride in the rear seat restrained with lap belts only. **Booster seats** have been shown to decrease the risk of injury by 59% and should be used by children once they outgrow their forward-facing child harness seat until at least 8 years of age and 4 ft 9 in (145 cm) tall. Many states have extended their car seat laws to include children of booster seat age as well. Shoulder straps placed behind the child or under the arm do not provide adequate crash protection and may increase the risk of serious injury. The use of lap belts alone has been associated with an increased risk of seatbelt-related injuries, especially fractures of the lumbar spine and hollow-viscus injuries of the abdomen. These flexion-distraction injuries of the spine are often accompanied by injuries to the abdominal organs.

The rear seat is clearly much safer than the front seat for both children and adults. One study of children <15 years old found that the risk of injury in a crash was 70% lower for children in the rear seat compared with those sitting in the front seat. Frontal **airbags** present a risk of serious or fatal injury from the airbag itself for children <13 years. Side airbags also pose a risk for children who are in the front seat and are leaning against the door at the time of a crash. **The safest place for children is in the rear middle seat, properly restrained for their age and size.** Educational and legislative interventions to increase the number of children traveling in the rear seat have been successful.

Children riding in the rear bed of pickup trucks are at special risk for injury because of the possibility of ejection from the truck and resultant serious injury. Preschool or younger children riding in a **school bus** should use a proper child restraint system. Older children (usually >65 lb) can ride safely in a large (>16 passenger) school bus because of compartmentalization of the bus. Smaller buses require child restraint systems with seat belts, and seat belts are recommended for all new school buses.

Transportation of **premature infants** presents special challenges. The possibility of oxygen desaturation, sometimes associated with bradycardia, among premature infants while in child seat restraints has led the American Association of Pediatrics (AAP) to recommend an observed trial of infants born at <37 weeks of gestational age in the seat before discharge and the use of oxygen or alternative restraints for infants who experience desaturation or bradycardia, such as seats that can be reclined and used as a car bed.

Teenage Drivers

Drivers 15-17 years old have more than twice the rate of collisions compared with motorists 18 years and older. Formal driver education courses for young drivers appear to be ineffective as a primary means of decreasing the number of collisions. The risk of serious injury and mortality is directly related to the speed at the time of the crash and inversely related to the size of the vehicle. Small, fast cars greatly increase the risk of a fatal outcome in the event of a crash.

The number of passengers traveling with teen drivers influences the risk of a crash. The risk of death for 17-year-old drivers is 50% greater when driving with one passenger compared with driving alone; this risk is 2.6-fold higher with two passengers and 3-fold higher with three or more passengers.

Teens driving at night are overrepresented in crashes and fatal crashes, with nighttime crashes accounting for >33% of teen motor vehicle fatalities. Almost 50% of fatal crashes involving drivers <18 years old occur in the 4 hours before or after midnight. Teens are 5-10 times more likely to be in a fatal crash while driving at night compared with driving during the day. The difficulty of driving at night combined with the inexperience of teen drivers appears to be a deadly combination.

Another risk factor for motor vehicle crashes for people of all ages, including teens, is **distracted driving**. Distracting events can include *visual* distraction (taking eyes from the forward roadway), *manual* distraction (removing hands from vehicle controls), or *cognitive* distraction (taking attention from navigating the vehicle or responding to critical events). **Electronic devices** present all three modes of distraction in combination and are increasingly recognized as a major threat to driver safety, especially among teens. The recent uptick in motor vehicle fatality rates per vehicle mile driven is generally believed to be caused by distracted driving.

* http://www.healthychildren.org/english/safety-prevention/on-the-go/pages/car-safety-seats-information-for-families.aspx.
† https://www.nhtsa.gov/equipment/car-seats-and-booster-seats.

In 2017, 39.2% of teen drivers reported they had texted or emailed while driving in the last 30 days. Dialing on a cell phone increases the risk of a crash almost threefold, and texting may increase the risk as much as sixfold. Although most states have banned text messaging for all drivers, the effect of state laws on prohibiting such behavior while driving is unknown. Parents should set limits on the use of these devices by their teens; technologic interventions that can block cell phone signals in a moving vehicle are also available and should be considered by parents for their teens.

Newer vehicles are increasingly equipped with driver assistance technology, electronic stability control, and automated crash avoidance systems. Despite the potential to reduce road traffic crashes and injury, these technologies are not yet prevalent in the vehicular fleet. In addition, there is evidence that many drivers do not understand the use, or limitations, of these technologies.

Graduated driver's licensing (GDL) programs consist of a series of steps over a designated period before a teen can receive full, unrestricted driving privileges. In a three-stage graduated license, the student driver must first pass vision and knowledge-based tests, followed by obtaining a learner's permit, and once a specific age has been achieved and driving skills advanced, the student driver is eligible to take the driving test. Once given a provisional license, the new driver will have a specified time to do low-risk driving. GDL usually places initial restrictions on the number of passengers (especially teens) allowed in the vehicle and limits driving at night. The number of crashes decreases 10–30% among the youngest drivers in states with a GDL system. The characteristics of GDL programs vary substantially across states. Optimal safety benefits depend on parent monitoring and engagement with teens around driving restrictions and responsibilities. Parent–teen driving contracts are available and help to facilitate these discussions.

Alcohol use is a major cause of motor vehicle trauma among adolescents. The combination of inexperience in driving and inexperience with alcohol is particularly dangerous. Approximately 20% of all deaths from motor vehicle crashes in this age-group are the result of alcohol intoxication, with impairment of driving seen at blood alcohol concentrations (BACs) as low as 0.05 g/dL. In 2019, approximately 16.7% of adolescents reported riding with a driver who had been drinking, and 5.4% reported driving after drinking. All states have adopted a *zero-tolerance policy* to adolescent drinking while driving, which defines any measurable alcohol content as legal intoxication. All adolescent motor vehicle injury victims should have their BAC measured in the ED and should be screened for high-risk alcohol use with a validated screening test (e.g., CRAFFT (https://crafft.org/); Alcohol Use Disorders Identification Test [AUDIT]) to identify those with alcohol abuse problems (see Chapter 157.1). Individuals who have evidence of alcohol abuse should not leave the ED or hospital without plans for appropriate alcohol abuse treatment. Interventions for problem drinking can be effective in decreasing the risk of subsequent motor vehicle crashes. Even brief interventions in the ED using motivational interviewing can be successful in decreasing adolescent problem drinking.

Another cause of impaired driving is **marijuana use**. In 2017, nearly 20% of high school students reported using marijuana in the prior 30 days, and 50% of current teen users reported driving after use. Marijuana is currently legal (2021) for adult use in 19 U.S. states and for medical use in 27 states, while being considered in many others; the effects of this on adolescent injury remain to be determined. Marijuana is often co-ingested with alcohol or other drugs, and blood thresholds for biologic impairment have not been standardized. It is therefore difficult to estimate the independent effect of marijuana on crash risk.

All-Terrain Vehicles

All-terrain vehicles (ATVs) in many parts of the United States are an important cause of injuries to children and adolescents. These vehicles can attain high speeds, especially with low-weight children, and are prone to rollover because of their high center of gravity. Orthopedic and head injuries are the most common serious injuries seen among children involved in ATV crashes. Helmets can significantly decrease the risk and severity of head injuries among ATV riders, but current use is very low. Voluntary industry efforts to decrease the risk of injuries appear to have had little effect in making ATVs safer. The AAP recommends that children <16 years old should not ride or drive ATVs.

Bicycle Injuries

Each year in the United States, approximately 122,000 children and adolescents are treated in EDs for bicycle-related injuries, making this one of the most common reasons that children with trauma visit EDs. The majority of severe and fatal bicycle injuries involve **head trauma**. A logical step in the prevention of these head injuries is the use of helmets. **Helmets** are very effective, reducing the risk of all head injury by 85% and the risk of traumatic brain injury by 88%. Helmets also reduce injuries to the mid and upper face by as much as 65%. Pediatricians can be effective advocates for the use of bicycle helmets and should incorporate this advice into their anticipatory guidance schedules for parents and children. Appropriate helmets are those with a firm polystyrene liner that fits properly on the child's head. Parents should avoid buying a larger helmet to give the child "growing room." If a crash occurs and the helmet is struck, it should be replaced.

Promotion of helmet use can and should be extended beyond the pediatrician's office. Community education programs spearheaded by coalitions of physicians, educators, bicycle clubs, and community service organizations have been successful in promoting the use of bicycle helmets to children across the socioeconomic spectrum, resulting in helmet use rates of ≥70% with a concomitant reduction in the number of head injuries. Passage of bicycle helmet laws also leads to increased helmet use.

Consideration should also be given to other types of preventive activities, although the evidence supporting their effectiveness is limited. Bicycle paths are a logical method for separating bicycles and motor vehicles.

Ski- and Snowboard-Related Head Injuries

The increasing use of helmets in snow sports, such as skiing and snowboarding, is encouraging because head injuries are the most common cause of death in these sports, and helmets reduce the risk of head injury by ≥50%. Use of helmets does not result in skiers or snow boarders taking more risks and should be encouraged in all snow sports at all ages, not just for young children.

Pedestrian Injuries

Pedestrian injuries are a major cause of traumatic death for children and adolescents in the United States and in most high-income countries. In low-income countries, a much higher proportion of road traffic fatalities are pedestrians, especially among 5- to 14-year-olds. Although case fatality rates are <5%, serious nonfatal injuries constitute a much larger problem, resulting in 29,233 ED visits in 2019 for children and adolescents. Pedestrian injuries are the most important cause of traumatic coma in children and a frequent cause of serious lower-extremity fractures, particularly in school-age children.

Most pedestrian injuries occur during the day, with a peak in the after-school period; thus improved lighting or reflective clothing would be expected to prevent few injuries. Surprisingly, approximately 30% of pedestrian injuries occur while the individual is in a marked crosswalk, reflecting a false sense of security and decreased vigilance in these areas. The risk of pedestrian injury is greater in neighborhoods with high traffic volumes, speeds >25 miles/hr, absence of play space adjacent to the home, household crowding, and low socioeconomic status.

One important risk factor for childhood pedestrian injuries is the developmental level of the child. Children <5 years old are at risk for being run over in the driveway. Few children <9 or 10 years of age have the developmental skills to successfully negotiate traffic under all circumstances. Young children have poor ability to judge the distance and speed of traffic and are easily distracted by playmates or other factors in the environment. Many parents are not aware of this mismatch between the abilities of the young school-age child and the skills needed to cross streets safely. The use of mobile phones and devices has become increasingly common while walking and can increase the risk of being struck by a motor vehicle.

Prevention of pedestrian injuries is difficult but should consist of a multifaceted approach. Education of the child in pedestrian safety should be initiated at an early age by the parents and continue into the school-age years. Younger children should be taught never to cross streets when alone; older children should be taught (and practice how) to negotiate quiet streets with little traffic. Major streets should not be crossed alone until the child is at least 10 years of age and has been observed to follow safe practices.

Legislation and police enforcement are important components of any campaign to reduce pedestrian injuries. Right-turn-on-red laws increase the hazard to pedestrians. In many cities, few drivers stop for pedestrians in crosswalks, a special hazard for young children. Engineering changes in roadway design are extremely important as passive prevention measures. Most important are measures to slow the speed of traffic and to route traffic away from schools and residential areas; these efforts are endorsed by parents and can decrease the risk of injuries and death by 10–35%. Other modifications include networks of one-way streets, proper placement of transit or school bus stops, sidewalks in urban and suburban areas, striping in rural areas to delineate the edge of the road, "road diets" to reduce lanes of traffic pedestrians must cross, and curb parking regulations. Comprehensive traffic "calming" schemes using these strategies have been very successful in reducing child pedestrian injuries in Sweden, the Netherlands, Germany, and increasingly, the United States.

Falls

Falls are the leading cause of **nonfatal injury** in children and adolescents. Altogether, there were 1.8 million falls that led to ED visits in 2019 for children and adolescents; approximately 2.9% of these visits led to a hospitalization or transfer. There have been relatively few in-depth analytic studies of falls, except in particular circumstances, such as playground injuries. Strategies to prevent falls depend on the environmental circumstances and social context in which they occur. *Window falls* have been successfully prevented with the use of devices that prevent egress, and injuries from *playground falls* can be mitigated through the use of proper surfacing, such as woodchips or other soft, energy-absorbing materials. Alcohol may also contribute to falls among teenagers, and these injuries can be reduced by general strategies to reduce teen alcohol use.

Fire- and Burn-Related Injuries

See Chapter 89.

Poisoning

See Chapter 94.

Drowning

See Chapter 88.

Traumatic Brain Injury

See Chapter 82.

Firearm Injuries

Injuries to children and adolescents involving firearms occur in three different situations: unintentional injury, suicide attempt, and assault. The injury may be fatal or may result in permanent sequelae.

Firearm related deaths (all causes) for youths (1-19 years) in 2020 was ~5.62 per 100,000 population. The rate was 17.4 for Black youths, compared to 3.4 for White youths. Firearm homicides represent 60% of firearm-related deaths in youths. In 2020, firearm-related deaths exceeded motor vehicle collisions as the leading cause of death for children and adolescents. **Unintentional firearm injuries** and deaths have continued to decrease and accounted for 426 deaths to children 0-18 years old in 2019, representing only a very small fraction of all firearm injuries among children and adolescents. The majority of these deaths occur to teens during hunting or recreational activities.

Suicide is the second most common cause of death from all causes in both males and females aged 10-19 years. During the 1950s to 1970, suicide rates for children and adolescents more than doubled; firearm suicide rates peaked in 1994 and decreased by 59% from this peak by 2010 before gradually increasing, paralleling increases in the overall suicide rate. The difference in the rate of suicide death between males and females is related to the differences in method used during attempts. Females die less often in suicide attempts because they use less lethal means (mainly drugs) and perhaps have a lower degree of intent. The use of firearms in a suicidal act results in an approximately 90% case fatality rate.

Homicides are third only to motor vehicle crashes and suicide among causes of death in teenagers >15 years old. In 2019, 2,023 adolescents aged 15-19 years were homicide victims; Black teenagers accounted for 64% of the total, making homicides the most common cause of death among this group. Over 85% of homicides among teenage males involved firearms, mostly handguns.

In the United States, approximately 32% of adults reported owning a gun in 2020, including 36% of adults who had children under 18 in the household. Home ownership of guns increases the risk of adolescent suicide 3- to 10-fold and the risk of adolescent homicide up to 4-fold. In homes with guns, the risk to the occupants is far greater than the chance that the gun will be used against an intruder; for every death occurring in self-defense, there may be 1.3 unintentional deaths, 4.6 homicides, and 37 suicides.

Handguns account for approximately 30% of the firearms in use today, yet they are involved in 80% of criminal and other firearm misuse. Of all firearms, **handguns** pose the greatest risk to children and adolescents. Access to handguns by adolescents is surprisingly common and is not restricted to those involved in gang or criminal activity. Stricter policies to reduce youth access to handguns, rather than all firearms, would appear to be the most appropriate focus of efforts to reduce shooting injuries in children and adolescents (Fig. 14.6).

Locking and unloading guns and storing ammunition locked in a different location substantially reduce the risk of a suicide or unintentional firearm injury among youth by up to 73%. Because up to 30% of handgun-owning households have at least one firearm stored unsafely, one potential approach to reducing these injuries could focus on improving household firearm storage practices where children and youth reside or visit. The evidence regarding the effectiveness of office-based counseling to influence firearm storage practice is mixed; the most effective programs are those in which safe storage devices are dispensed along with advice.

Adolescents with mental health conditions and alcoholism are at particularly high risk for firearm injury. In the absence of conclusive evidence, physicians should continue to work with families to eliminate access to guns in these households.

Violent Behavior and Aggression

Although the current rates of homicide are much lower than at their peak in the late 1980s and early 1990s, the problem of violence and assault remains large. The origins of adult and teen violence occur during childhood. Almost all adults who commit violent acts have a history of violent behavior during childhood or adolescence. Longitudinal studies following groups of individuals from birth have found that aggression occurs early and that most children learn to control this aggression in childhood. Children who later become violent adolescents and adults do not learn to control this aggressive behavior.

The most successful interventions for violence target young children and their families. These include home visits by nurses and paraprofessionals beginning in the prenatal period and continuing for the first few years of life to provide support and guidance to parents, especially parents without other resources. Enrollment in early childhood education programs (e.g., Head Start) beginning at age 3 years has been shown to be effective in improving school success, keeping children in school, and decreasing the chance that the child will experience delinquency in adolescence. School-based interventions, including curricula to increase the social skills of children and improve the parenting skills of caregivers, have long-term effects on violence and risk-taking behavior. Early identification of behavior problems by primary care pediatricians can best be accomplished through the routine use of formal screening tools. Interventions in adolescence, such as family therapy, multisystemic therapy, and therapeutic foster care, can decrease problem behavior and a subsequent decline into delinquency and violence.

PSYCHOSOCIAL CONSEQUENCES OF INJURIES

Many children and their parents have substantial psychosocial sequelae from trauma. Studies in adults indicate that 10–40% of hospitalized injured patients will have **posttraumatic stress disorder** (PTSD; see Chapter 38). Among injured children involved in motor vehicle

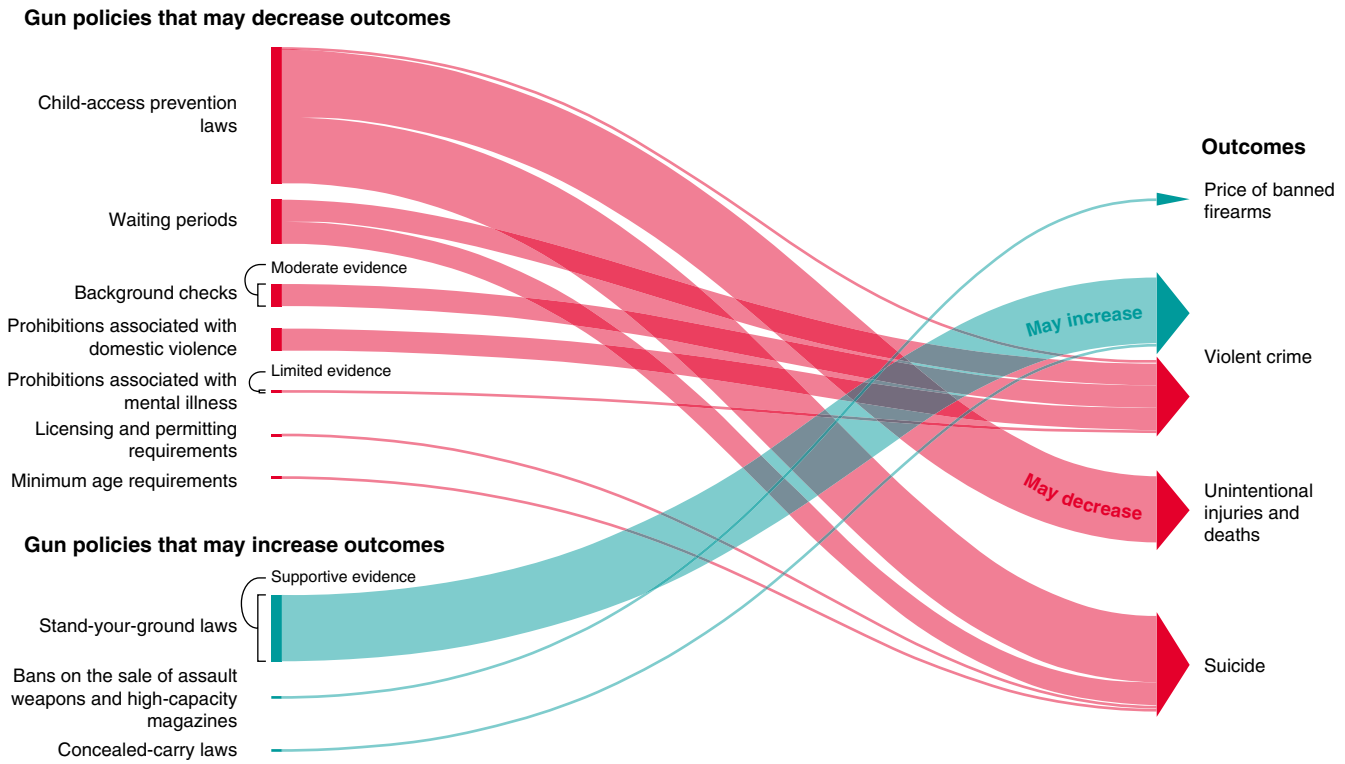

Fig. 14.6 Gun policy–based outcomes. (*Adapted from Gun Policy in America/RAND*. https://www.rand.org/research/gun-policy.html.)

crashes, 90% of families will have symptoms of **acute stress disorder** after the crash, although the diagnosis of acute stress disorder is poorly predictive of later PTSD. Standardized questionnaires that collect data from the child, the parents, and the medical record at the time of initial injury can serve as useful screening tests for later development of PTSD. Early mental health intervention, with close follow-up, is important for the treatment of PTSD and for minimizing its effect on the child and family.

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Chapter 15

Impact of Violence Exposure on Children

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The reach of violence—whether as the victim, perpetrator, or witness, whether in person or through the media—is far, deep, and long-standing across the globe. In the home, it is estimated that 80–95% of children and youth witness such aggression. In general, the types of violence children are exposed to increases in severity as children grow older. *Exposure to violence* disrupts the healthy development of children in a myriad of ways. Pediatric clinicians must be aware of violence exposure and competent to address its impact on children and families under their care (**trauma-informed care**). Trauma-informed care gives pediatric clinicians the tools to assess childhood trauma and adversity experiences as well as practical guidance, resources, and interventions. Clinicians also have a wider responsibility to advocate on local, state, national, and international levels for safer environments in which all children can grow and thrive (see Fig. 14.6).

We know that many traumatic events during childhood can have immediate and long-term impact (**adverse childhood experiences;** see Chapter 1). Adversity in the first years of life may deleteriously affect the course of human development throughout the life span, and **witnessing violence** is one such adversity. Because bystanders who witness violence can have permanent emotional and behavioral effects due to neurophysiologic alterations, healthcare providers may not fully appreciate their distress and thereby miss an opportunity to provide needed interventions. For children not living in war zones, the source of first exposure to violence is often **intimate partner violence (IPV)**. In the United States alone, >1 in 15 children witness IPV each year, and worldwide approximately 275 million children are exposed to IPV yearly. Exposure to IPV in infancy and toddlerhood affects attachment relationships, and school-aged youth who witness IPV have difficulties in developing and maintaining friendships, have difficulty in school, may abuse drugs and alcohol, and may develop mental health problems.

Another source of witnessed violence is **community violence**, a serious problem in the United States that disproportionately affects children from low-income areas. Approximately 22% of children witness violence in their family or in their community each year; *witnessed violence* includes assaults and bullying, sexual victimization, maltreatment by a caregiver, and theft or vandalism. Almost 60% of children will experience or witness violence during childhood. Witnessing acts of violence may be a significant stressor in children's lives. Witnessed community violence is related to internalizing problems such as depression and posttraumatic stress disorder (PTSD), as well as externalizing problems, including delinquent behavior, aggression, and substance abuse.

The most ubiquitous source of witnessing violence for U.S. children is **media violence**, sometimes referred to as **virtual violence**. This form

of violence is not experienced physically; rather it is experienced in realistic ways through technology and ever more intense and realistic games. There is an ever-widening array of screens that are part of children's everyday lives, including computers, tablets, and cell phones, in addition to long-standing platforms, such as televisions and movies. Tragic events, including mass shootings and acts of terrorism, have increased the specter of fear among children as these events are reenacted for them on the multiple screens they encounter. Although exposure to media/virtual violence cannot be equated to exposure to real-life violence, many studies confirm that media/virtual violence *desensitizes* youth to the meaning and impact of violent behavior. Violent video game exposure may be associated with increased aggressive behavior; increased aggressive cognitions; increased aggressive affect, increased desensitization, and decreased empathy; and increased physiologic arousal. Violent video game use is a risk factor for adverse outcomes; however, insufficient data exist to examine any potential link between violent video game use and delinquency or criminal behavior. Table 15.1 lists interventions to reduce exposure to media violence.

IMPACTS OF VIOLENCE

All types of violence have a profound impact on health and development, physiologically, psychologically, and behaviorally potentially leading to the challenges mentioned earlier. It may influence how children view the world and their place in it. Children can come to see the world as a dangerous and unpredictable place. This fear may thwart their exploration of the environment, which is essential to learning in childhood. Youth may experience overwhelming terror, helplessness, and fear, even if they are not immediately in danger. Young children are most vulnerable to threats that involve the safety (or perceived safety) of their caretakers. Chronic exposure to violence predisposes children to subsequent mental health problems and can have a deleterious effect on learning and neurodevelopment. High exposure to violence in older youth correlates with poorer performance in school, symptoms of anxiety and depression, and lower self-esteem. Violence, particularly IPV, can also teach youth especially powerful early lessons about the role of violence in relationships. Violence may change the way that children view their future; they may believe that they could die at an early age and thus take more risks, such as drinking alcohol, abusing drugs, not wearing a seatbelt, and not taking prescribed medication. Violence exposure is an important childhood adversity that is known to increase the risk for poor health in adults.

Some children exposed to severe and/or chronic violence may suffer from PTSD, exhibiting constricted emotions, difficulty concentrating, autonomic disturbances, and reenactment of the trauma through play or action (see Chapter 38). Based on the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5) criteria for PTSD in children ≤6 years old, >50% of preschoolers may experience clinically significant symptoms of PTSD after exposure to IPV. Although young children may not fully meet these criteria, certain behavioral changes are associated with exposure to trauma, such as sleep disturbances, aggressive behavior, new fears, and increased anxiety about separations (clinginess). A challenge in treating and diagnosing pediatric PTSD is that a child's caregiver exposed to the same trauma may be suffering from it as well.

Table 15.1 Public Health Recommendations to Reduce Effects of Media Violence on Children and Adolescents

1. Parents should:
- Be made aware of the risks associated with children viewing violent imagery, as it promotes aggressive attitudes, antisocial behavior, fear, and desensitization.
- Review the nature, extent, and context of violence in media available to their children before children view it.
- Assist children's understanding of violent imagery appropriate to their developmental level.
- Be aware and monitor social media access/use of youth

2. Professionals should:
- Offer support and advice to parents who allow their children unsupervised access to extreme violent imagery, as this could be seen as a form of emotional abuse and neglect.
- Educate all young people in critical film appraisal in terms of realism, justification, and consequences.
- Exercise greater control over access to inappropriate violent media entertainment by young people in secure institutions.
- Use violent film material in anger management programs under guidance.

3. Media producers should:
- Reduce violent content and promote antiviolence themes and publicity campaigns.
- Ensure that when violence is presented, it is in context and associated with remorse, criticism, and penalty.
- Ensure that violent action is not justified or its consequences understated.

4. Policymakers should:
- Monitor the nature, extent, and context of violence in all forms of media and implement appropriate guidelines, standards, and penalties.
- Ensure that education in media awareness is a priority and a part of school curricula.

From Browne KD, Hamilton-Giachritsis C. The influence of violent media on children and adolescents: A public-health approach. *Lancet.* 2005;365:702–710.

Diagnosis and Follow-Up

The simplest way to recognize whether violence exposure has affected a family is to screen both the caregivers and the youth (after approximately 8 years of age) on a regular basis. This practice is particularly important during pregnancy and the immediate postpartum period, when women may be at highest risk for being abused. It is important to assure families that they are not being singled out, but that all families are asked about their exposure to violence. In the case of IPV, it is important to ask the caregivers separately to maintain safety and mitigate risk for the caregiver who is being abused.

A direct approach may be useful: "Violence is a major problem in our world today and one that impacts everyone in our society. So I ask all my patients and families about violence that they experienced growing up as well as now. . . ." This can take the form of a three-generation family history of violence exposure. In other cases, beginning with general questions and then moving to the specific may be helpful: "Do you feel safe in your home and neighborhood? Has anyone ever hurt you or your child?" When violence has affected the child, it is important to gather details about symptoms, behaviors, and protective factors that support resilience.

The pediatric clinician can effectively counsel many parents and children who have been exposed to violence. Regardless of the type of violence to which the child has been exposed, the following components are part of the guidance: (1) careful review of the facts and details of the event, (2) referring to support services, (3) providing information about the symptoms and behaviors common in youth exposed to violence, (4) assistance in restoring a sense of stability to the family in order to enhance the youth's feelings of safety, and (5) helping caregivers talk to their children about the event. Families should be referred to a mental health professional when (1) the violence is significant, (2) symptoms are chronic (>6 months) or not improving, (3) if the violent event involved the death or departure of a parent, (4) if the caregivers are unable to empathize with the child, or (5) if the ongoing safety of the child is a concern.

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15.1 Bullying, Cyberbullying, and School Violence

Megan A. Moreno and Elizabeth Englander

BULLYING AND CYBERBULLYING

Bullying behavior affects people throughout the life span, but much of the focus has been on children and adolescents. In the past, bullying was sometimes considered a rite of passage or was written off as "kids being kids." However, it is well recognized that bullying can have profound short- and long-term negative consequences on all those involved, including perpetrators, targets, and bystanders. The consequences of bullying can affect a child's social experiences, academic progress, and health.

Bullying is defined as any unwanted aggressive behavior by another youth or group of youths that involves an actual or perceived power imbalance and is repeated multiple times or is highly likely to be repeated. Generally, sibling aggression and dating violence are excluded, but research has associated these problems with *peer bullying*. Digital technology was initially viewed as a context in which bullying can occur. **Cyberbullying** is not merely bullying that occurs through electronic communications, but rather a type of bullying with distinct elements, such as the potential for a single event to "go viral" and the use of technology as a tool to achieve power imbalance.

It is thought that bullying and cyberbullying are more alike than dissimilar and that surveillance efforts, as well as prevention and intervention approaches, should address both types of bullying.

Bullying Roles and Nomenclature

Bullying represents a dynamic social interaction in which an individual may play different roles at different stages. A child can be a perpetrator of bullying, a target of bullying, a witness or bystander, or simply a child whose environment is affected by pervasive bullying. In any bullying experience, the roles that each child plays may be fluid, such that a target of bullying may then become a perpetrator, or vice versa. Thus common nomenclature has evolved to refer to children as *perpetrators* of bullying or *targets* of bullying to represent a present state, rather than labeling a child as a bully or a victim, which suggests a static role and may affect that child's self-image.

Epidemiology

Bullying is a widespread problem during childhood and adolescence. Current estimates suggest that school-based bullying likely affects 18–31% of children and youth and that cyberbullying affects 7–15% of youth. Apparent rates of bullying are influenced by the questions that are asked; the word "bully" is stigmatized, and absent that label, youth are more willing to acknowledge having engaged in activities that can be categorized as bullying. Estimates of bullying prevalence are typically based on self-reported victimization (not perpetration), but here too, language can influence results. Targets of other types of social conflict may overestimate or underestimate their bullying victimization unless precise language is used during assessment.

Risk Factors

Certain groups are more vulnerable to bullying, including youth who are lesbian, gay, bisexual, transgender, and questioning (LGBTQ+); immigrant and ethnic/racial minoritized youth; obese youth; and youth with disabilities. However, it is important to recognize that although these individual risk factors exist, the context and situation can also present unique risk factors. Some studies have found that Black children are bullied more often than Latinos, whereas other studies have found no group differences. Contextual factors, such as the school climate or prevalence of a particular ethnic group in a school setting, may be important factors in a given bullying situation. The 2019 Youth Risk Behavior Survey found that White teens were much more likely than Black teens to report experiencing any bullying. Thus it is important to recognize that any individual being bullied is embedded within a situation that is within a larger social context. This *person by situation by context* approach is useful to consider in identifying why bullying takes place in some situations but not others.

Bullying may occur with other high-risk behaviors. Students who carry weapons, smoke, and drink alcohol are at higher risk for engaging in bullying. Negative parenting behavior is related to a moderately increased risk of becoming a *bully/victim* (youth who are both perpetrators and targets) and small to moderate effects on being targeted for bullying at school.

Some risk factors may be specific to cyberbullying. Among preadolescent children, more access to technology (e.g., cell phone ownership) predicts cyberbullying behaviors and some types of digital victimization. Also, communications through digital technology can be misperceived as hostility, and those misperceptions can in turn increase electronic forms of bullying.

Consequences of Bullying

Involvement in any type of bullying is associated with poorer psychosocial adjustment; perpetrators, targets, and those both perpetrator and target report greater health problems and poorer emotional and social adjustment. Consequences of both traditional and cyber forms of bullying are particularly significant in the areas of physical health, mental health, and academic achievement. Being the target of bullying is typically viewed as particularly stressful. The impact of this stress has been shown to affect the developing brain and to be associated with changes to the stress response system, which confers an increased risk for future health and academic difficulties. The long-term consequences of being bullied as a child include increased risk for depression, poor self-esteem, and abusive relationships. Negative outcomes for perpetrating bullying include higher risks of depression and substance abuse. Mental health consequences for both perpetrator and target include, across types of bullying, increased risks of depression, poor self-esteem, increased suicidality, and anxiety. Academic difficulties include increased risk of poor school performance, school failure, and dropping out.

SCHOOL VIOLENCE

Epidemiology

School violence is a significant problem in the United States. Almost 40% of U.S. schools report a least one violent incident to police, with >600,000 victims of violent crime per year. Among 9th to 12th graders, 8% were threatened or injured on school property in the last 12 months, and 14% were involved in a physical fight over the last year. Still, school-associated violent deaths are rare. Seventeen homicides of children aged 5-18 years occurred at school during the 2009–2010 school year. Of all youth homicides, <2% occur at school. Although urban schools experience more episodes of violence, the rare rampage gun violence that happens in rural and suburban schools demonstrates that no region is immune to lethal violence.

Risk Factors

Bullying and weapon carrying may be important precursors to more serious school violence. Among perpetrators of violent deaths at school, 20% had been bullying victims, and 6% carried a weapon to school in the last 30 days. Nonlethal violence, mental health problems, racial tensions, student attacks on teachers, and the effects of rapid economic change in communities can all lead to school violence. Individual risk factors for violence include prior history of violence, drug, alcohol, or tobacco use, association with delinquent peers, poor family functioning, poor grades in school, and poverty in the community.

Family risk factors include early childbearing, low parental attachment and involvement, authoritarian or permissive parenting styles (see Chapter 20), and poverty. There is more school violence in areas with higher crime rates and more street gangs, which take away students' ability to learn in a safe environment and leave many children with traumatic stress and grief reactions.

TREATMENT AND PREVENTION OF BULLYING AND SCHOOL VIOLENCE

Pediatric providers are in a unique position to screen, treat, and advocate for reducing the impact of bullying and school violence by assisting those affected and seeking to prevent further occurrences.

Signs and Symptoms

Signs of a child being involved in bullying or exposed to school violence include physical complaints such as insomnia, stomachaches, headaches, and new-onset enuresis. **Psychologic symptoms**, such as depression (see Chapter 39), loneliness, anxiety (see Chapter 38), and suicidal ideation, may occur. **Behavioral changes**, such as irritability, poor concentration, school avoidance, and substance abuse, are common. **School problems**, such as academic failure, social problems, and lack of friends, can also occur. Additional vigilance is warranted for those children who represent vulnerable groups for bullying and aggression, including youth with disabilities; obesity; or minority, immigrant, or LGBTQ+ status.

Screening for Bullying

Assessing bullying and cyberbullying involvement is an important part of pediatric visits. Several tools can be helpful for clinicians, including the *Bright Futures Guidelines,* which recommend screening at each well-child visit. In these discussions, begin by normalizing the conversation; for example, practitioners can let the patient know that bullying is a topic they discuss with all their patients. It is advisable to define bullying based on the uniform definition but using readily understandable and developmentally appropriate language. Physicians can ask patients if they have had experiences where there was repeated cruelty or "mean actions" between peers, either as a target of that cruelty or seeing the cruelty, or even being angry or mean toward others. Asking a patient if he or she is a bully is not likely to generate either trust or an honest answer. Asking about exposures to peer victimization or school violence is also important. Throughout these discussions, it is critical to provide support and empathy while engaging a patient.

One tool to help providers begin and navigate these discussions is a *Practice Enhancement Tool* developed by the **Massachusetts Aggression Reduction Center** (MARC) and Children's Hospital Boston (Fig. 15.1). It begins by defining bullying in readily understandable language and then asks, "Is there any one kid, or a bunch of kids, that pick on you or make you feel bad over and over again?" The tool also guides the practitioner in asking about problematic digital experiences and asks whom the child has spoken to about the problem and whether that has helped. Finally, it guides the practitioner through emphasizing the usefulness of talking about social problems and discusses how the physician can assist the patient.

Children who are aggressive, overly confident, lacking in empathy, or have persistent conduct problems may need careful screening. It is important to bear in mind that bullying is a dynamic process, and a child may be involved as both a perpetrator and a target at different time points. The physical, behavioral, psychologic, and academic symptoms of bullying may overlap with other conditions, such as medical illness, learning problems, and psychologic disorders. Thus labeling the behavior as *bullying* rather than the child as a "bully" is recommended.

Management of bullying and school violence involves several steps. First, ensure that all parties understand the relevant information (the patient, parents, and school). Second, assess a child's need for specialized counseling or social skills interventions. Extracurricular activities (e.g., drama clubs, mentoring programs, sports) can be discussed as avenues to help increase the child's social skills and self-esteem. Third, ensure that the patient has adequate support, including at home and at school. Peers are a particularly effective source of support, and patients can be encouraged to spend time with friends, but parents and educators are also important sources of emotional support. Many children benefit from planning their actions in unstructured settings (e.g., discussing where they could sit during lunch), whereas some benefit from role-playing. Finally, the clinician should identify safety issues, such as suicidal ideation and plans, substance abuse, and other high-risk behaviors.

When bullying or cyberbullying is suspected or confirmed, the parents and child should be offered education and resources. Some resources include the government-supported website www.stopbullying.gov, as well as MARC. Both provide free downloadable literature that can be offered to parents and families.

Addressing cases of bullying or exposure to violence in clinic often requires a cross-disciplinary approach. Involving teachers or school counselors, as well as outside referrals to psychologists, social workers, or counselors, may be warranted. Parental mental health and resource risk factors should also be addressed.

Prevention

Pediatric clinicians can reasonably expect their patients' schools to provide violence and bullying prevention programs. Rather than focusing on only changing a target of bullying, successful interventions use whole-school approaches that involve multiple stakeholders. **School climate** has been shown to have significant effects on bullying prevalence, so these approaches are essential to primary prevention. These broad-based programs simultaneously include school-wide rules and sanctions, teacher training, classroom curriculum, and high levels of student engagement. Addressing access to firearms, involving community organizations and parents, and supporting youth mental health are important in creating a safe school climate.

Prevention programs for cyberbullying are at a nascent stage, reflecting uncertainty about the prevalence of the practice, who is perpetrating it and from where, and how students respond when they are victimized. Many schools have established cyberbullying policies and are increasingly involved with teaching youth about guidelines for appropriate online interactions and monitoring for cyberbullying problems. As of 2016, 23 states included cyberbullying in their state antibullying laws, and 48 states included "electronic harassment." Although legal remedies are frequently not the most productive answer to bullying and cyberbullying incidents, pediatric clinicians should be aware of local laws and be prepared to refer parents to more information about these laws when necessary. Studies suggest that preventive interventions designed to address bullying have effects on cyberbullying, and vice versa.

The American Academy of Pediatrics (AAP) provides a free online **Family Media Use Plan** that allows families to develop rules for digital media use and prompts for discussions about safety and online relationships with the goal of preventing negative consequences of online behavior and interactions. The tool is designed for ongoing discussions with family members about online experiences and family rules and values.

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15.2 Media Violence

Megan A. Moreno

Today's youth are growing up in a media-rich environment of both traditional and digital media. *Traditional* media includes television (TV), radio, and periodicals; *digital* media includes online content that promotes interactive and social engagement. The online world allows youth instant access to entertainment, information, and knowledge; social contact; and marketing. Social and interactive media allow users to act as both creators and consumers of content. Examples include applications (apps), social media, multiplayer video games, YouTube videos, and video blogs (vlogs).

One of the earliest studies that has been linked to media effects on aggression and violence was the "bobo doll" experiment in which children who observed an aggressive adult model were more likely to be aggressive toward a doll afterward. It has been widely accepted that media exposure can affect behavior; the advertising industry is grounded in the concept that media exposure can change purchasing behavior. Exposure to sexual content in media has been linked to earlier sexual initiation; exposure to pro-alcohol content

MARC/BACPAC Pediatric Questionnaire: **Bullying & Cyberbullying**

Date of office visit:_____

Child's name: _____	Gender: ☐Male ☐Female
Child's grade: _____	Child's age: _____ years _____ months
IEP? ☐Yes ☐No	Neurodev / Psych Dx (if established): _____

Parent present during interview? ☐Yes ☐No

Subjective complaints (eg, H/A, tics, sleep):

_____

_____

BEGIN BY STATING:

"You probably know that grownups today are very worried about bullying. I'd like to ask you a little bit about that, but I want to make sure you understand what I mean. When I ask about bullying, I mean another kid (or group of kids) who picks on someone or is mean to them on purpose, over and over again – not just one time."

1. Do you see bullying happen at your school?

☐ **Yes** ☐ **No**

2. Is there any one kid or a bunch of kids that pick on you or make you feel bad over and over again?

☐ **Yes** (inquire as to the frequency):

(_____ times daily; _____ times a week; _____ times a month; _____ times a year).

IF NO, SKIP TO **#3**

If YES:
Where does this happen? (check all that apply):

☐ classroom ☐ lunchroom ☐ hallways
☐ stairwell ☐ bathroom ☐ locker-room
☐ playground ☐ bus ☐ other: _____

What did he or she do to you? (check all that apply):

☐ made fun of me ☐ kids laughed ☐ name-calling
☐ rumors ☐ made up lies ☐ got me in trouble
☐ pushed, shoved, hit, threw stuff ☐ other:_____

3. How about on the computer at home? Has anyone been mean to you or made fun of you on the internet?

☐ **Yes** (Details):

_____

_____

If **NO** to both **#2** and **#3, END HERE.** Otherwise, continue.

Fig. 15.1 MARC/BACPAC* pediatric questionnaire on bullying and cyberbullying. *Massachusetts Aggression Reduction Center and Bullying and Cyberbullying Prevention and Advocacy Collaborative. (*Copyright 2013 Peter C. Raffalli, MD, and Elizabeth Englander, PhD.*)

Continued

MARC/BACPAC Pediatric Questionnaire: **Bullying & Cyberbullying**

4. It's very important that you understand that if you are being bullied that it is *never* your fault. Bullying is wrong and people should *never* bully others. Have you told any adults about the kids that are bothering you?

☐ **Yes** (Who have you told?)

- ☐ Parent
- ☐ Teacher
- ☐ Other: _____

If Yes.....Were the adults able to stop the bullying?

☐ **Yes** ☐ **No**

If Yes.....Did talking about it make you feel better?

☐ **Yes** ☐ **No** ("That's ok. Sometimes talking does help though.")

5. "Sometimes it feels good just to talk about things. I wish you and I had more time to talk about it today. Would you like to have a chance to talk about it sometime soon?"

☐ **Yes** (if YES, refer to):

_____

_____

☐ **No**

IF NO...

..."Would you like me to try to help? As your doctor, I can talk with the school officials and try to make sure that the bullying stops. While I cannot promise that everything will be better, I know that if we do nothing the bullying will likely continue and probably get worse. I want you to be happy and safe at school — is it okay with you if I talk to your school about this?"

☐ **Yes**
(Who would you like me to talk to? Principal / Nurse / Counselor / Teacher / Other: _____)

☐ **No**

Fig. 15.1 cont'd

MARC/BACPAC Pediatric Questionnaire: **Bullying & Cyberbullying**

Guide to the bullying/cyberbullying checklist/interview

"Warm up" questions: briefly acknowledge these but do not discuss at length. No need to note the child's answers.

- Are the kids in your school friendly?
- Tell me about one child at your school who you like.
- Tell me about one child at your school who is not friendly.

(Brief acknowledgement, e.g.: "Ok" or "that's good.")

Note: It's fine to skip the warm-up questions if you have already chatted with the child.

Websites for parents/ teachers/students:

The Massachusetts Aggression Reduction Center (MARC): **MARCcenter.org**

Bullying And Cyberbullying Prevention and Advocacy Collaborative (BACPAC) at Boston Children's Hospital: **bostonchildrens.org/BACPAC**

Stop Bullying Now from the U.S. government: **stopbullying.gov**

When a child is being bullied

There are three venues through which you can help this child:

1. **BY GIVING THEM A "SAFE ADULT" AT SCHOOL THEY CAN ALWAYS SPEAK WITH (EG, THE SCHOOL NURSE, THE SCHOOL ADJUSTMENT COUNSELOR);**
2. **BY GIVING THEIR PARENTS GUIDANCE ABOUT HOW TO COPE (THROUGH HANDOUTS, WEBSITES); AND**
3. **BY OFFERING THEM SUPPORT FROM YOURSELF.**

If child consents to your involvement, seek written parental consent to share information with the school in writing. The more details the child can provide as to who, what, where, how, the more power the school will have to act. Explain this to the child/parent and do your best to gently get details for your letter to the school. If child or parent will not consent to communication with school, provide advice / handouts (**MARCcenter.org**) to help the parent advocate themselves for their child with the school. Always document in your note the conversation in the office.

Fig. 15.1 cont'd

has been linked to earlier alcohol initiation. However, applying these same constructs to media violence has been controversial. Some suggest that other concepts may be important to consider, such as "dose-response" effects of media or gene-environment interactions.

There are three main types of media in which children may be exposed to violence: video games, traditional media, and social media. **Violent video game** exposure is associated with several outcomes, including increases in composite aggression score, aggressive behavior, aggressive cognitions, aggressive affect, and desensitization; decreased empathy; and increased physiologic arousal. Several mechanisms for these outcomes have been studied. These have included evaluating links between video game violence and the limbic or reward areas of the brain, as well as through other cognitive processes, including skill acquisition, cognitive control, and attention.

Traditional media such as movies and TV often model violent behavior for the purposes of entertainment. Media violence does not always portray the real human cost or suffering caused by violence. Special effects can make virtual violence more believable and appealing than in the real world. For some children, exposure to media violence can lead to anxiety, depression, posttraumatic stress disorder, or sleep disorders and nightmares. Repeated exposure to the behavioral scripts provided by entertainment media can lead to increased feelings of hostility, expectations for aggression, desensitization to violence, and increased likelihood of interacting and responding to others with violence.

Social media presents similar risks of exposure to virtual violence, but because of the interactive nature of the medium, this content can feel more personal, relevant, or targeted. Social media combines peer and media effects and thereby represents a powerful motivator of behavior, whether content created by adolescents themselves or content they find and share with peers. The Facebook Influence Model describes 13 distinct constructs in which social media may influence users, such as establishing *social norms* and connection to identity. Thus exposure to violent content on social media may have an influence in promoting a social norm or connecting this type of content to one's own identity.

SCREENING

It is important for pediatricians to screen and counsel patients and families about media use and exposure to violent content. Both the quantity and the quality of media are critical factors in media effects on children. When heavy media use by a child is identified, pediatricians should evaluate the child for aggressive behaviors, fears, or sleep disturbances and intervene appropriately.

RECOMMENDATIONS (SEE TABLE 15.1)

Pediatricians can counsel parents to help their children **avoid exposure to any form of media violence under age 8 years**. These younger children do not have the capacity to distinguish fantasy from reality.

Parents should **select and co-view media with their children**, including playing video games with them, watching movies together, and co-viewing social media content. Parents can then assess these games and shows in regard to what they are teaching about communication and interactions with others.

Parents should **feel empowered to place restrictions** on games or shows that reward shooting, killing, or harming other people. Media are powerful teachers, and parents can make choices about how much violence they want their children to learn. Parents can use industry ratings, such as from the Motion Picture Association of America and the Entertainment Software Ratings Board for movies and TV, as well as resources such as Commonsense Media (which also includes video game reviews), to guide media selections.

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15.3 Effects of War on Children

Isaiah D. Wexler and Eitan Kerem

The adverse consequences of war on children are devastating and long-lasting—death, injury, loss of family members, conflict-associated sexual violence, food insecurity, forced relocation (prejudice and discrimination in the receiving country), coercive conscription, child abduction, and psychologic trauma. Human rights organizations and the Secretary General of the United Nations annually detail the extent and impact of war on children. These reports clearly establish that war is a global phenomenon associated with a staggering intensity of human rights violations involving children. Approximately 426 million live in a conflict zone, and ~1.6 billion children (0-18 years) live in a conflict-affected country (Fig. 15.2). The recent onset of large-scale hostilities between Russia and Ukraine in 2022 has had a significant impact on children, especially displacement.

During the last decade, there has been an increase in armed conflict–associated exploitation in the form of **human trafficking**, slavery, forced marriages, prostitution, and child labor. **Displacement** and forced relocation are on the rise as a result of the increasing number of intrastate conflicts, especially in the Middle East and Africa. In 2020, UNHCR **(Office of the United Nations High Commissioner for Refugees)** reported the

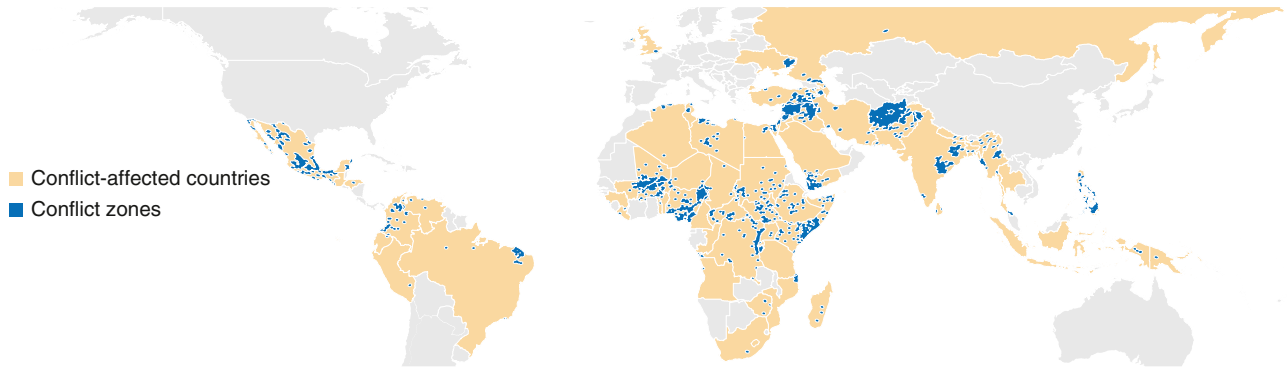

Fig. 15.2 Conflict-affected countries and conflict zones, 2019. Overlays of the conflict-affected countries with the conflict zones where actual fighting took place in 2019. Conflicts are usually concentrated in limited geographical areas within countries. (*From Østby G, Rustad SA, Tollefsen AF. Children affected by armed conflict, 1990–2019. Conflict Trends, vol 6. Oslo: PRIO;2020: Figure 1. https://www.prio.org/publications/12527.*)

astounding statistic of 82.4 million people forcibly displaced worldwide, with most of the refugees being sheltered in developing countries that lack adequate resources to deal with large-scale humanitarian crises. In Ukraine, the United Nations Office for the Coordination of Humanitarian Affairs reported that 2 million children had been internally displaced at the end of 2022. Reemergence of polio or cholera and the increased virulence of tuberculosis have been associated with conflict-affected regions and large population displacements. The COVID-19 pandemic that began in 2020 has worsened the existing situation, with widespread disruption of health and educational services provided by domestic healthcare systems and humanitarian organizations.

Mortality and morbidity related to the long-term effects of war and civil strife are as significant as those occurring during actual fighting. War and violence are rarely listed as leading causes of childhood mortality, but the regions with the highest levels of child mortality, especially among children <5 years of age, are the same locations involved in military conflicts. Nations experiencing conflict often devote substantial portions of their budgets to military expenditures at the expense of the healthcare infrastructure; a substantial proportion of deaths attributed to malnutrition, environmentally related infectious disease, or inadequate immunization are related to the effects of war. Children experiencing the trauma of wartime violence are at risk for long-term health sequelae, with greater risk for obesity, hypertension, stroke, and cardiovascular disease.

During wartime, customary patterns of behavior are forced to change, overcrowding is frequent, and essential resources, such as water and food staples, may be polluted or contaminated. There is a growing understanding that war and climate change are linked. Armed conflict can worsen the impact of spreading desertification, and competition for scarce resources can serve as a stimulus for war.

The morbidity of children exposed to conflicts is significant and long-term (Table 15.2). Many more children are physically harmed than killed. Children bear the psychologic scars of war resulting from exposure to violent events, loss of primary caregivers, and forced removal from their homes. Impressment of children into service as **soldiers** is a form of *exploitation* associated with long-term problems of adjustment. Child soldiers often lack the appropriate education and socialization, and thus their moral compass is often misaligned. They are often incapable of understanding the sources of conflict or why they have been targeted. Their thought processes are more concrete; it is easier for them to dehumanize their adversaries. Children, who themselves are exposed to violence and cruelty, frequently become the worst perpetrators of atrocities.

After cessation of hostilities, children are still at risk for life-endangering injuries from **landmines**, unexploded ordinance, and other explosive remnants of war. Before the signing of the international treaty to ban landmines in 1997, an estimated 20,000-25,000 casualties occurred annually from landmines. Despite the ban, there are still a significant amount of casualties reported, with over 7,000 casualties in 2020 according to *Landmine and Cluster Munition Monitor*, a nongovernmental organization monitoring adherence to the international treaty. Approximately 30% of these casualties occur in children, with a predominance of males. The continued proliferation of small arms and light weapons, which are easily handled by children, also continues to take its toll on human life and hinders stabilization in post conflict societies.

SUSCEPTIBILITY OF CHILDREN IN TIMES OF WAR

Children do not have the physical or intellectual capabilities to defend themselves. It is easier for adults to victimize children than other adults. Older children's curiosity, desire for adventure, and imperfect assessment of risk often lead them to participate in dangerous behavior. Younger children, because of their small size and immature physiology, are more susceptible to disease and starvation and are more likely to sustain fatal injuries from ballistic projectiles and explosive devices such as mines. **Blast injuries**, a common cause of violence-related injuries, have a more devastating impact on children than on adults. Specific types of military engagement can have a disproportionate effect on children. In a survey of war-related mortality in Iraq from 2003 to 2008, it was found that approximately 10% of the violence-related fatalities were children. Most children succumbed to either small arms gunfire or suicide bombs (35%). Data collected during the Syrian civil war from 2011 to 2016 showed that 17% of the approximately 100,000 fatal civilian casualties were children, with over 70% of male children succumbing as a result of artillery shelling or aerial bombardments.

Table 15.2 Impact of War on Children

PHYSICAL
Death
Sexual violence (pregnancy, genital trauma, STIs)
Amputations and fractures
Head trauma
Ballistic wounds
Blast injuries
Burns
Chemical- and biologic-induced respiratory disease
Malnutrition and starvation
Infectious disease
Toxicity from polluted natural resources
Torture
PSYCHOSOCIAL
Abduction
Displacement
Loss of caregivers and family members (orphaned)
Child assuming adult roles (labor, parenting sibling)
Separation from community
Lack of education
Inappropriate socialization
Acute stress reaction
Posttraumatic stress disorder
Depression
Maladaptive behavior
EXPLOITATION
Conscription as soldiers
Coerced involvement in terrorist activities
Prostitution
Slavery
Forced adoption

STI, Sexually transmitted infection.

During times of war, there is a breakdown of social inhibitions and cultural norms. Exploitation of children, such as forced marriages or involuntary conscription, are rationalized as being beneficial for the greater cause. Aberrant behavior such as rape, torture, and pillaging, which would be inconceivable in times of peace, is common during war. Children may be attacked, kidnapped, or used as human shields.

The changing nature of war has adversely affected children. Conventional warfare in which armies of professional soldiers representing different countries battle each other has become less common since World War II, with the notable exception of the Russia-Ukraine war **Intrastate conflicts** in the form of civil war or insurgency predominate. In 2020, there were over 50 active intrastate armed conflicts in the world, as documented by the *Uppsala Conflict Data Program* (UCDP). These conflicts are often rooted in factious ethnic, political, or religious ideologies, and the participants are frequently nonprofessional irregulars who lack discipline and accountability to higher echelons and are directed by those who do not acknowledge or respect international accords governing warfare. Often the military resources of the antagonists are disproportionate, leading the weaker protagonist to develop compensatory

tactics that can include guerrilla, paramilitary, and terrorist activities, while the stronger side often resorts to the disproportionate use of force. Low-intensity conflicts have become more common. These types of conflicts are often characterized by military activities targeting civilian populations with the goal of disrupting normal routines and generating publicity for the perpetrators. Sites of violence can be remote from the battleground when one or both parties to a conflict resort to terrorist activities.

Terrorism and organized urban-based **gang warfare** have become prevalent. Violence perpetrated by terrorist groups or gangs is designed to coerce and intimidate both individuals and entire societies. Children are often intended victims of political- or religious-motivated violence because this serves to maximize the impact of terrorism. The destruction of the New York City World Trade Center Towers in 2001 and the nearly 3,000 fatalities showed that highly organized and motivated terrorists have few inhibitions and can strike anywhere. **Biologic** and **chemical** weapons of mass destruction have been employed, with the most recent example being the use of poisonous gases in the Syrian civil war. Children are more susceptible to chemical and biologic toxins because of their higher respiratory rates, more permeable skin, and other developmental vulnerabilities (see Chapter 763).

The media and the internet have had a significant role in exacerbating the effects of war on children. Media coverage of war and terrorist events is extensive and visual, and social media promulgated via the internet is a convenient tool for disseminating **propaganda** and graphic video material designed to recruit volunteers and shock opponents. Children, more impressionable than adults, often view this material uncontrolled. Uncensored pictures of victims, unbridled violence, people in shock, or family members searching through ruins for relatives may traumatize children and even encourage inappropriate behavior. Overt broadcast propaganda glorifying war and violence may sway children to participate in militaristic or antisocial activities (see Chapter 15.2).

Table 15.3 Manifestations of Stress Reactions in Children and Adolescents Exposed to Armed Conflict

CHILDREN ≤6 YR
Excessive fear of separation
Clinging behavior
Uncontrollable crying or screaming
Freezing (persistent immobility)
Sleep disorders
Terrified affect
Regressive behavior
Expressions of helplessness and passivity
CHILDREN 7-11 YR
Decline in school performance
Truancy
Sleep disorders
Somatization
Depressive affect
Abnormally aggressive or violent behavior
Irrational fears
Regressive and childish behavior
Expressions of fearfulness, withdrawal, and worry
ADOLESCENTS 12-17 YR
Decline in school performance
Sleep disturbances
Flashbacks
Emotional numbness
Antisocial behavior
Substance abuse
Revenge fantasies
Suicidal ideation
Withdrawal

PSYCHOLOGIC IMPACT OF WAR

Exposure to war and violence can have a significant impact on a child's psychosocial development. Displacement, loss of caregivers, physical suffering, and the lack of appropriate socialization all contribute to abnormal child development. Often the reactions are age specific (Table 15.3). Preschoolers may have an increase in somatic complaints and sleep disturbances and display acting-out behaviors such as tantrums or excessively clinging behavior. School-aged children may show regressive behavior such as enuresis and thumb sucking. They, too, have an increase in somatic complaints; there is often a negative impact on school performance. For teenagers, psychologic withdrawal and depression are common. Adolescents often exhibit trauma-stimulated acting-out behavior. Motivated by the desire for revenge, they may be quick to join in the violence and contribute to the continuation of conflict.

There is an increased incidence of both **acute stress reactions** and **posttraumatic stress disorder** (PTSD; see Chapter 38). The true incidence is difficult to assess because of the heterogeneous nature of war, degree of exposure to violence, and methodologic challenges related to the precise characterization of PTSD. Risk factors for having a more serious psychologic response to a violent event include severity of the incident, personal involvement (physical injury, proximity, loss of a relative), prior history of exposure to traumatic events, female gender, and a dysfunctional parental response to the same event. Children may develop PTSD many years after the traumatic event. Children do not have to be directly exposed to violent activity, and media coverage of terrorist events may be sufficient to trigger PTSD-like symptomatology.

The trauma experienced by children during war can have lifelong effects. Studies on children imprisoned in concentration camps or evacuated from their homes in London during the Battle of Britain show that these individuals were at greater risk for PTSD, anxiety disorders, and a higher level of dissatisfaction with life when surveyed decades after the traumatic events. Depression is often a comorbid condition associated with PTSD among children exposed to armed conflict. Trauma may have a **transgenerational effect**, with biologic stress responses and environmental influences causing children of PTSD victims to display a wide variety of psychologic disorders. On the positive side, children are more resilient than adults. With appropriate support from family and community, together with timely and intensive psychologic intervention, children can recover and lead normal, productive lives despite the searing trauma that they may have experienced.

EFFORTS TO PROTECT CHILDREN FROM THE EFFECTS OF WAR

International Conventions

War and terror violate the human rights of children, including the right to life, the right to be nurtured and protected, the right to develop appropriately, the right to be with family and community, and the right to a healthy existence. Several international treaties and conventions have been ratified, beginning with the **Fourth Geneva Convention** (1949) that set forth guidelines regarding appropriate treatment of children in times of war. The **United Nations Convention on the Rights of the Child** (1990) delineated specific human rights inherent to every child (defined as any individual younger than 18 years) and the subsequent **First Optional Protocol** (2000), which prohibits conscripting or recruiting children for military activities. The **Third Optional Protocol** in 2014 established methods for communicating complaints of human rights violations involving children to the United Nations Committee on the Rights of the Child and sets up procedures by which the committee can

conduct inquiries into alleged human rights violations among signatory nations. The **Rome Statute of the International Criminal Court** enacted in 2002 declared that the conscription or enlistment of children younger than 15 years is a prosecutable war crime. Despite these conventions and better documentation, human rights violations have not abated. In the past decade there has even been an upswing in the recruitment of child soldiers as combatants by nonstate armed groups (NSAGs).

Although these treaties and conventions define the extent of protection afforded to children, the means of enforcement available to the international community is limited. Individuals, motivated by religious fervor, nationalistic zeal, or ethnic xenophobia, are unlikely to curb their activities because of fear of prosecution. These treaties better serve in heightening awareness regarding the protected status of children in wartime, and perhaps deter high-ranking leaders who fear being held accountable for war crimes.

Humanitarian Efforts

Several organizations, either nongovernmental or under UN auspices, are involved in mitigating the effects of war on children. The International Red Cross, UNICEF, UNHCR, International Rescue Committee, World Health Organization (WHO), and Médicins Sans Frontières (Doctors Without Borders) have had a significant impact on reducing violence-related casualties in war-torn regions. During the Russia-Ukraine war, many countries sent medical teams including pediatricians to Ukraine and neighboring countries hosting refugees to provide assistance. The infusion of humanitarian aid into developing countries often improves overall mortality and morbidity by increasing the level of medical and social services available to the general population. Other organizations, such as Amnesty International, Stockholm International Peace Research Institute, and Physicians for Human Rights, actively monitor human rights abuses involving children and other civilian groups. In 2005 the UN Security Council approved the establishment of a monitoring and reporting system designed to protect children exposed to war. UN-led task forces conduct active surveillance in war-stricken regions reporting on the **six grave violations against children during armed conflict:** the killing or injuring of children, recruitment of child soldiers, attacks directed against schools or hospitals, sexual violence against children, abduction of children, and denial of humanitarian access for children.

ROLE OF PEDIATRICIANS AND ALLIED HEALTH PROFESSIONALS

War is a chronic condition, and health providers need to be prepared to treat childhood casualties resulting from military or terrorist activity, as well as caring for children suffering from the aftermath of war or related violence. Community and hospital pediatricians need to be involved in community disaster planning. General disaster planning should not ignore the unique needs and requirements of children; in planning for a possible chemical attack, appropriate resuscitation equipment suitable for children needs to be stockpiled. The signs of biologic infection, chemical intoxication, or radiation injury are different for children, and pediatricians and emergency personnel need to be aware of these differences (see Chapters 758 and 763). Surveys of pediatricians and other healthcare providers indicate that many feel unprepared for bioterrorism attacks. Professional organizations (e.g., WHO, American Academy of Pediatricians [AAP], Centers for Disease Control and Prevention [CDC]) have published position papers, and the AAP *Red Book* presents guidelines for treating specific pathogens likely to be used in **biologic warfare**. In regions where violent terrorist activity is likely, pediatricians, nurses, and rescue personnel should obtain certification provided by Red Cross Basic and Advanced Trauma Life Support programs. The U.S. Department of Health and Human Services sponsors a *Technical Resources, Assistance Center, and Information Exchange* (TRACIE) website that includes information for health service providers related to disaster management and preparedness for incidents involving children (asprtracie.hhs.gov).

Pediatricians need to be aware of the potential effects of war and terror on parents and children. Loss or separation from parents or caregivers has a devastating impact on children (see Chapter 30). Parents, who themselves are under tremendous strain, may not be sensitive to the effects that the same stressors have on their children. Parents and caregivers must be made cognizant of the effect that media coverage can have on their children and their role in the intermediation of the repetitive broadcast of real-time acts of violence and incendiary communications designed to enlist support for specific causes. Pediatricians should draw out both parents and children and encourage them to talk freely about their feelings. Child healthcare providers can be instrumental in educating parents to be more aware of inappropriate responses by children to war and violence. When necessary, pediatricians can serve their families by referring them to appropriate support services.

Just as it is important to administer first aid for physical trauma, it is also critical to provide psychologic first aid to victims of trauma. An excellent source of online information for both providers and caregivers is the **U.S. government–sponsored National Child Traumatic Stress Network** (nctsn.org). In day-to-day patient interactions, a pediatrician is most likely to confront situations related to stress reactions such as PTSD or depressive disorders. Recognition of PTSD is essential so that early treatment can be initiated. The *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5) stipulates that for a diagnosis of PTSD, there has to be manifestations from each of four symptom clusters: *intrusion, avoidance, negative alterations in cognitions and mood,* and *alterations in arousal and reactivity*. DSM-5 also established a special preschool subtype of PTSD that has the same four symptom clusters but with specific manifestations typical of preschoolers exposed to trauma. Clues to the presence of PTSD and acute anxiety reactions include changes in behavior, school performance, affect, and sleep patterns and an increase in somatic complaints. Even when the triggering event is neither temporally nor physically proximate, it should not dissuade the pediatrician from making an appropriate referral to mental health professionals who are expert in childhood stress disorders.

Medical professional standards demand that the physician treat all patients equitably without regard to their background. Both international law and professional medical societies ban physicians from actively participating in **torture** or other activities that infringe on human rights, including those of children. It is difficult to countenance any situation in which a health professional, even acting as a representative of their country, might directly or indirectly injure a minor. On the positive side, many pediatricians and other physicians have treated children during war either as members of the armed services or volunteers, often under adverse conditions, refusing to abandon their patients even when it has put their own lives at risk. Pediatricians and pediatric organizations have been at the forefront in advocating for peaceful coexistence, assisting in relief efforts, and attempting to alleviate the disparities in healthcare resulting from war.

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Chapter 16

Child Trafficking for Sex and Labor

V. Jordan Greenbaum

Human trafficking violates the fundamental human rights of affected children, adolescents, and adults and affects families, communities, and societies. Trafficked persons originate from countries worldwide and may belong to any racial, ethnic, religious, socioeconomic, or cultural group. They may be of any gender. According to the United Nations *Protocol to Prevent, Suppress and Punish Trafficking in Persons,* **child trafficking** refers to the "recruitment, transportation, transfer, harboring or receipt of a person" under 18 years old for purposes of exploitation. Two major types of trafficking involve **forced labor** and **sexual exploitation** (Table 16.1). Whereas adult sex trafficking requires demonstration of force, fraud, coercion, deception, or the abuse of power as a means of exploitation, these are *not* required for persons younger than 18 years. Interpretation of the international protocol varies across the globe; U.S. law does not require movement of a victim to qualify as human trafficking. In addition, minors who "consent" to commercial sex in the absence of a third party (trafficker) are victims of commercial sexual exploitation, because their age precludes true informed consent.

Child trafficking may occur within the confines of the child's home country (*domestic* trafficking) or may cross national borders (*international,* or *transnational,* trafficking). Globally, individuals tend to be trafficked within their own country or to a country in the same region. In the United States, most identified children and adolescents experiencing *sex trafficking* are U.S. citizens or legal residents; few statistical data exist on minors who are trafficked for labor. Variations in definitions of terms, problems with data collection, and underrecognition of affected individuals complicate estimates of the prevalence of human trafficking, but the International Labour Organization estimates that approximately 3.3 million children and adolescents across the globe experienced forced labor in 2021, of whom approximately 1.7 million were subjected to commercial sexual exploitation. In a global study of officially identified trafficked persons, the United Nations Office on Drugs and Crime estimated that approximately 19% were girls and 15% boys. However, laws that define sexual exploitation in terms of females and women, as well as cultural views regarding gender roles, lead to underreporting of males, especially as victims of sex trafficking, so their numbers may be higher than estimated.

Table 16.1 Types of Exploitation Included in Child Trafficking

Sexual Exploitation
Prostitution of a child
Production of child sexual exploitation materials (child pornography)
Exploitation in context of travel and tourism
Having a minor perform sex acts in a sexual venue (e.g., strip club)
Child marriage or forced marriage
Live online sexual abuse
Labor Exploitation
Agriculture, manufacturing, textiles, food/hospitality services
Domestic work
Construction
Magazine sales
Health and beauty
Cleaning services
Forced Begging
Forced Criminality
Forced Engagement in Armed Conflict
Illegal Adoption

Factors creating vulnerability to human trafficking exist at the individual, relationship, community, and societal levels (Table 16.2). **Age** is an important risk factor for adolescents because they are at a stage in their development at which they have limited life experience, a desire to demonstrate their independence from parental control, and a level of brain maturation that favors risk-taking and impulsive behaviors over careful situational analysis and other executive functions. They are also very interested in social media and are savvy at internet use, which render them susceptible to online recruitment and solicitation.

Recruitment of children and adolescents for labor or sex trafficking often involves false promises of romance, job opportunities, or a better life. Individuals may remain in their exploitative situation for a number of reasons, including **fear of violence** to themselves or their loved ones should they attempt to leave their situation; **guilt and shame** for believing the fraudulent recruitment scheme or engaging in illegal and/or socially condemned activities; **humiliation** and fear of criticism by authorities; **debt bondage** (believing they owe the trafficker exorbitant amounts of money and cannot leave until the debt is paid); and fear of **arrest** and/or **deportation**. Many children and adolescents do not view their situation as exploitative. Females who believe their trafficker is a boyfriend may view their commercial sexual activities as demonstrations of their love; males engaging in commercial sex to obtain shelter or food while living on the street may feel they are exploiting buyers rather than being victimized themselves. Traffickers may use violence, economic manipulation, and psychologic manipulation to control individuals.

CLINICAL PRESENTATION

Children and adolescents who experience trafficking may seek medical care for any of the myriad physical and emotional conditions associated with exploitation. They may present with traumatic injuries inflicted by traffickers, buyers, or others or injuries related to unsafe working conditions. They may present with a history of sexual assault or symptoms/signs of sexually transmitted infections (STIs) and infections related to overcrowded, unsanitary conditions. They may request testing for HIV or complain of signs/symptoms of HIV or infections endemic to their home country (e.g., malaria, schistosomiasis, tuberculosis). Other clinical presentations may involve pregnancy and complications of pregnancy or abortion; malnutrition and/or dehydration; exhaustion; conditions related to exposure to toxins, chemicals, and dust; and signs and symptoms of posttraumatic stress disorder (PTSD), major depression, suicidality, behavioral problems including aggression, and somatization. Some children and adolescents may have preexisting chronic medical conditions that have been inadequately treated before or during the exploitation (e.g., diabetes, seizure disorder, asthma). Individuals who are trafficked may also seek medical care for their children.

Many of the same factors that prevent children and adolescents from leaving their exploitative conditions also preclude them from disclosing their situation to others. Most affected individuals presenting for medical care at clinics, hospitals, and emergency departments do not spontaneously self-identify as trafficked persons. Consequently, it is incumbent on the medical professional to be aware of risk factors so that those being trafficked and those at risk may be recognized and offered services. A trafficked individual may present to a medical facility alone, in the company of a parent/guardian (who may or may not be aware of the trafficking situation), a friend or other person not involved in the trafficking, a person working for the trafficker (who may pose as a friend or relative),

Table 16.2 Risk Factors for Child Trafficking

INDIVIDUAL
Member of marginalized group (e.g., racial, ethnic, sexual minority, caste)
History of sexual/physical abuse or neglect
Limited education
Unaccompanied immigrant status
Substance misuse
Homeless/runaway status; told to leave home
History of child welfare and/or juvenile justice involvement (U.S., sex trafficking)
Untreated mental or behavioral health condition
RELATIONSHIP
Family poverty
Family violence, substance misuse, or other dysfunction
Forced migration
Family/peers involved in trafficking
Intolerance of LGBTQ+ status
Significantly older intimate partner
COMMUNITY
Limited resources (economic, educational, social support)
Tolerance of trafficking/exploitation
Natural disaster
Community violence
Limited knowledge of trafficking/exploitation
Increased tourism, travel to area
SOCIETAL
Cultural beliefs about roles and rights of children
Gender bias/discrimination
Cultural beliefs and practices that marginalize and disempower groups (e.g., transphobia, xenophobia)
Tolerance of exploitation
Systemic racism and discrimination
Tolerance of violence
Societal/economic/health inequity and inequality
Social or political upheaval
Inadequate laws regarding trafficking; corruption

LGBTQ+, Lesbian, gay, bisexual, transgender, queer/questioning, and other.

Table 16.3 Potential "Red Flags" for Child Trafficking

RED FLAGS AT PRESENTATION
Chief complaint of acute physical or sexual assault
Chief complaint of suicide attempt or ideation
Patient accompanied by unrelated adult or juvenile
Patient or parent accompanied by domineering person who appears in hurry to leave
Patient or parent appears intimidated or fearful
Patient or accompanying person provides inconsistent or unlikely history of events
Patient unfamiliar with city/town, cannot provide address where staying
PHYSICAL FINDINGS
Patient withdrawn and with flat affect, fearful, very anxious, intoxicated, or with inappropriate affect
Evidence of remote or acute inflicted injury (suspicious burns, bruising, signs of strangulation, fractures, closed head injury, thoracoabdominal trauma)
Evidence of preventable work injury, toxic exposure, overuse injury, or untreated injury
Malnutrition with or without dehydration
Poor dentition and/or dental trauma
Late presentation of illness/injury

or the trafficker. Traffickers may be male or female, adult or juvenile, and they may be family members, acquaintances, friends, or strangers. On occasion, children and adolescents are brought in by law enforcement or child protective services because of concerns of trafficking. Table 16.3 lists potential "red flags" for labor or sex trafficking. In some cases, the red flag may be the **chief complaint**, which may involve a condition frequently associated with trafficking (e.g., STI symptoms/signs, especially with history of prior STI, and a preventable work-related injury such as a toxic exposure). The practitioner may become concerned about possible trafficking on recognizing the presence of one or more **risk factors** (e.g., runaway status, recent migration and current work in a sector known for labor trafficking).

APPROACH TO THE PATIENT AT RISK FOR TRAFFICKING

When interacting with a patient who may have experienced labor or sex trafficking, the medical provider should use a **trauma-informed, human rights–based, culturally appropriate, and gender-sensitive approach** (Table 16.4). This involves an awareness that trauma experienced by a young person may influence the child's thoughts about themselves and others, their beliefs and perceptions of the world, and their behavior. Hostility, withdrawal, or distrust may be reactions to trauma and should be met with a sensitive, nonjudgmental, empathic response by the provider. Physical safety of the patient and staff are critical, and protocols should be in place to address security issues that may arise if the trafficker is on the premises. Psychologic safety of the patient may be facilitated by separating them from any accompanying person when obtaining the medical history, conducting the visit in a warm, child-friendly environment, and taking adequate time to build rapport and begin to establish trust. When interpretation is needed, a professional interpreter should be used. This person needs to be trained in trauma-informed care and should not be from the same community as the patient. When possible, the patient's preference for gender of clinician and interpreter should be respected.

Respect for the **patient's rights** is essential, including the right to an explanation regarding the purpose of the questions being asked and the reasons for, and elements of, the examination and diagnostic evaluation. Informed assent by the patient for all steps of the process should be obtained whenever possible. Every attempt should be made to understand and respect cultural, gender-based, and religious factors that may affect the individual's views of their bodies, their condition, and their desired treatment.

The limits of confidentiality should be explained in a way the patient understands so that they are able to choose what information to disclose. This should occur before asking sensitive questions. As appropriate to developmental stage and the context of the visit, the provider should discuss how sensitive information is to be documented in the individual's medical record and work collaboratively to honor the patient's preferences and desire for privacy and confidentiality (within the bounds of laws, policies, and the need to ensure appropriate continuity of care).

Currently, there are limited child trafficking screening tools designed for the healthcare setting. The Short Screen for Child Sex Trafficking (SSCST) is validated for youth 11-17 years who present to emergency departments, child abuse clinics, and teen clinics; this tool screens for risk factors associated with sex trafficking; a positive screen indicates a child is at risk, and additional follow-up questions are needed to assess the level of risk and to determine next steps (e.g., specific service referrals, mandatory reporting). It does not screen for labor trafficking. The Quick Youth Indicators of Trafficking (QYIT) is a short screen designed for young adults

Table 16.4 Elements of a Human Rights–Based, Trauma-Informed Approach to Patient Care

BASIC RIGHTS
Best interest of the child to be primary concern in all actions involving the child
Protection from discrimination because of gender, race, ethnicity, culture, socioeconomic status, disability, religion, language, country of origin, or other status
Right to express views and be heard appropriate to the child's age and development
Right to obtain information relevant to the child to be given in a way that the child can understand
Right to privacy and confidentiality
Right to the highest attainable standard of health and to access healthcare services
Right to dignity and self-respect
Right to consideration of special needs (e.g., age, disability)
Right to respect of cultural and religious beliefs and practices
TRAUMA-INFORMED CARE
A strength-based approach that facilitates patient resilience and empowerment.
Obtain medical history in a private, safe place, outside the presence of persons accompanying the patient to the visit.
Explain all processes in way the patient understands, and obtain assent for each step; discuss the limits of confidentiality and mandated reporting.
Encourage the patient to express views and to participate in decision-making regarding referrals and care.
Foster the patient's sense of control during the evaluation.
Ask only the questions needed to assess safety, health, and well-being. Avoid asking irrelevant questions about trauma to avoid unnecessarily triggering anxiety and distress.
Minimize retraumatization during history, examination, and diagnostic testing (avoid triggers of stress when possible).
Monitor for signs of distress, both verbal and nonverbal.
Allow the patient to choose the gender of the provider, if feasible.
Have trained personnel present during the examination to assist with providing support and reassurance.
Avoid making promises the provider cannot fulfill.
Put information gathered to good use.
Work with the child to conduct a safety assessment and create a plan.
Be prepared to make referrals and offer resources.

(18-25) seeking services at a homeless shelter; it screens for both labor and sex trafficking.

When a provider is speaking with a child at perceived risk for trafficking, additional questions may be asked once trust has been established. These should be asked using a trauma-informed approach. For example,

- "Many children who are living on the street have a hard time getting money for food and shelter. Sometimes they have to exchange sex to get what they need. Has this ever happened to you or anyone you know?"
- When asking about sexual history: "Has anyone ever asked you or forced you to have sex with another person? Do you feel comfortable telling me about it?"
- "If you feel comfortable, can you tell me a little bit about your job? Is the work you do what you expected when you agreed to the job? Are you allowed to keep all of the money you earn or send it home? Where, and with whom, do you live? When you are not working, are you allowed to come and go from the place you stay?"

Such questions may open the door to a discussion of exploitation and facilitate the provider identifying appropriate resources and referrals.

All elements of the medical history and review of systems are important, but special attention should be paid to reproductive history (including sexual orientation and gender identity, prior history of sex partners, STIs, pregnancy and terminations, and condom use); injury history; substance use/misuse; and mental health history and current symptoms. Rates of substance misuse, PTSD, depression, and suicidality are very high among individuals experiencing human trafficking, and questioning may highlight the need for emergency care or nonurgent referrals. It also provides an opportunity for anticipatory guidance aimed at harm reduction: a discussion of condom use, STIs, HIV/AIDS, and substance use may prove invaluable, because many youth lack accurate information on these topics. It is important to identify any chronic conditions, especially if untreated, and to assess vaccination status. Many individuals who have experienced trafficking have had very poor healthcare in the past and lack basic primary care. It is important to ask questions about signs/symptoms of infections endemic to the child's home country or to countries in which the child has been trafficked (e.g., tuberculosis, dengue, malaria; see Chapter 11).

EXAMINATION AND DIAGNOSTIC TESTING

A thorough physical examination allows the provider to assess and treat acute and chronic medical conditions, collect forensic evidence (as appropriate), assess nutritional and developmental status, and document recent and remote injuries. Diagnostic testing may identify pregnancy, STIs, HIV seroconversion, nonsexually transmitted infections, vitamin and mineral deficiencies, anemia, toxic exposures, and drug or alcohol use. A sexual assault evidence kit may reveal trace evidence or DNA from offenders. Informed assent for the exam, assault kit, and diagnostic tests is important, as is careful explanation of each step during the process and monitoring of the patient for signs of distress and anxiety. Those who have been sex-trafficked may experience particular distress during the anogenital examination, the oral exam, and when injuries are photographed. A trauma-trained chaperone is very helpful in providing comfort and support to the patient. The examination should be conducted outside the presence of anyone suspected of being involved in the trafficking situation. After the exam the provider should explain the results, ask the patient if they have any questions about the exam, and give them the opportunity to discuss concerns about their bodies. Individuals who experience trafficking may harbor anxiety about a variety of issues, including possible infertility, future health, or possible permanent damage from work-related injuries and toxic conditions.

Providers may follow U.S. Centers for Disease Control and Prevention (CDC) guidelines on STI testing and prophylaxis. Additional resources on laboratory testing for sexually and nonsexually transmitted diseases may be obtained from the CDC (https://www.cdc.gov/) or World Health Organization (WHO) websites (http://www.who.int/en/). In general, STIs of greatest relevance include *Neisseria gonorrhoeae, Chlamydia trachomatis, Trichomonas vaginalis,* HIV, syphilis, and hepatitis B and C viruses. Methods of testing and decisions to treat (e.g., positive test results vs prophylaxis vs syndromic treatment) will depend on national guidelines and on medical resources, which may be limited in some countries or regions. However, consideration should be given to the high likelihood that the patient may be lost to follow-up after the visit, so the decision to delay treatment until test results are available may lead to lack of needed medication. Testing and treatment decisions need to be outlined in a protocol. Emergency contraception and other methods of birth control (especially long-acting reversible contraception) should be discussed with the patient as feasible.

Many individuals who have been trafficked (and children of trafficked adults) have experienced nutritional deprivation, lack of immunizations, and general poor health, especially if they are from low-resource countries or are born into the trafficking situation. Guidance on **medical screening** and care for immigrant children (see Chapter 11) also may be obtained from the CDC (https://www.cdc.gov/immigrantrefugeehealth/guidelines/refugee-guidelines.html) or American Academy of Pediatrics

(AAP) *Red Book* or *Immigrant Child Health Toolkit* (https://aapca1.org/resource/aap-immigrant-child-health-toolkit/). Consideration should be given to vaccine-preventable diseases (including tetanus if there are open wounds) and common diseases in the patient's home country. Trafficked individuals may have iron deficiency, hemoglobinopathies, vitamin D deficiency, and undiagnosed vision or hearing problems. Crowded, unhygienic living conditions during the trafficking period raise the risks of tuberculosis, scabies, and diarrheal illnesses. Toxic levels of lead or chemicals may be present, and vitamin/mineral deficiencies should be considered. A **developmental or educational assessment** is important, given the high likelihood of poor primary care in the past and possible harsh living conditions.

Documentation of overall health and identified injuries is extremely important and should be detailed and accurate. Body diagrams and photographs (if not traumatizing to the patient) are helpful, as are written descriptions of injury location, type (e.g., contusion, laceration), size, shape, and color. All photographs should include patient identifiers and a measuring instrument when possible. Distance photographs to establish injury location may be supplemented with close-up photographs from various angles. Physical signs of untreated illness, malnutrition, and other conditions need to be documented carefully. When documenting the medical history, direct quotes should be used when possible (quotes of provider and of patient statements). Records, including written, video, audio, and photographic records, should be stored in a secure health information system, with limited access and password protection. Strict protocols for patient confidentiality and privacy should be established and followed.

REFERRALS AND RESOURCES

Before discharge, the provider should ensure the patient understands the results of the evaluation and has the opportunity to ask questions. A **risk assessment** should be done by the provider or other qualified staff, to include a discussion with the individual of safety concerns (involving current risks and perceived risks after discharge). The provider should engage the patient in establishing a **treatment plan** as developmentally appropriate. Transparency and shared decision-making are key elements of a trauma-informed approach. Healthcare providers must comply with mandatory reporting laws in their state or country, but in doing so, should make every effort to avoid causing harm to the patient or their family. If a mandatory report is necessary, this should be discussed with the patient before making the call to authorities, so the individual is aware of actions being taken. For nonmandated referrals, patient permission is needed.

For those practicing within the United States, assistance on interpreting laws, working with individuals who may have been trafficked, making reports to authorities, and identifying local referral sources may be obtained by contacting the **National Human Trafficking Hotline** (1-888-373-7888). The hotline has trained staff to assist trafficked persons and professionals alike, including interpreters for over 200 languages. Additional assistance may be obtained by contacting state or local law enforcement and antitrafficking task forces or local child advocacy centers (free-standing or hospital-based facilities that provide services for children and families who have experienced child abuse and/or neglect). In other countries, "helplines" and "hotlines" may be used to seek assistance for those who are being trafficked and those at risk. It is important for the healthcare provider to be aware of local, state, and national resources for individuals experiencing human trafficking.

Affected patients have numerous needs that extend beyond the range of the healthcare provider's ability to respond. A multidisciplinary team approach is needed to ensure the child is provided with necessary food, shelter, crisis management, language interpretation, immigration assistance, mental health and medical care, educational needs, and other services. Such a team may include local victim service providers, shelter staff, behavioral health professionals, child protective services (CPS) workers, law enforcement, child advocacy center staff, representatives of sexual assault crisis centers, and victim advocates. Potential health-related referrals may be found in Table 16.5. To increase the likelihood that the patient and family will obtain the services they desire, it is helpful for the provider to make a "warm handoff" to a referral agency, either contacting agency staff directly or allowing the patient/trusted caregiver to make the call to the agency before leaving the health facility.

Table 16.5 Potential Health Referrals for Trafficked Persons

Behavioral health assessment and treatment (emergent or nonurgent): trauma-focused, preferably conducted by a professional trained in trauma therapies*
Substance use assessment/treatment
Obstetrician/gynecologist
Specialized medical service
Primary medical home (for immunizations including HPV; HIV PrEP; periodic STI testing; monitoring of growth and development; family planning and reproductive health; anticipatory guidance; and nutrition/hygiene counseling)
Physical therapy, occupational therapy
Developmental assessment
Dentist
Optometrist or audiologist
Resources for LGBTQ+ individuals
HIV clinic
Child advocacy center (for second opinion on anogenital exam; forensic interview, behavioral health services)

*Appropriate therapy may differ with victims from varied cultures; there is a limited evidence base for the effectiveness of behavioral health therapy for children experiencing trafficking. However, in the United States, therapies with an evidence base for child sexual assault/abuse are often adapted for use.

HPV, Human papillomavirus; HIV PrEP: human immunodeficiency virus pre-exposure prophylaxis; STI, sexually transmitted infection; LGBTQ+, lesbian, gay, bisexual, transgender, queer/questioning, and other.

Children and adolescents who experience trafficking may face considerable **discrimination** and **social stigma** from the public and from professionals. They may be viewed as "consenting" participants, "illegal immigrants" who somehow "deserve" maltreatment, or "bad" youth who are responsible for their own actions. They may face discrimination related to risk factors such as poverty, gender identity, or systemic racism. In some countries, laws on sexual exploitation do not include boys, and cultural beliefs foster the attitude that males cannot be victimized. This complicates service provision and support for male patients who have experienced trafficking. Variations in the age of consent may result in a child being considered an adult in one country and a child in another, the former condition limiting access to adequate support or increasing the likelihood of being viewed as a criminal offender. For these reasons and others, it is important for the healthcare provider to advocate for the patient's best interests when interacting with other professionals and emphasize the need for comprehensive, sustained, trauma-informed services.

If responsible for long-term care of the patient, the provider should consider that treatment needs change over time, so treatment plans must be reevaluated periodically. Continuity of care is important but can be challenging when the individual is moved to another city, is transported back to the home country, or is retrafficked. Ongoing communication with external agencies and other healthcare providers can be extremely helpful, along with assignment of a case manager to help ensure referrals are in place in destination towns or villages.

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Chapter 17

Abused and Neglected Children

Howard Dubowitz and Wendy G. Lane

The abuse and neglect (maltreatment) of children are pervasive problems worldwide, with short- and long-term physical and mental health, cognitive, social, and economic consequences. Primary care professionals (PCPs) serving children have an important role in helping address this problem. In addition to their responsibility to identify maltreated children and help ensure their protection, health, and well-being, PCPs can also play vital roles related to prevention, treatment, and advocacy. While securing a child's safety is a priority, the child welfare system also aims to improve families' functioning and enable them to adequately care for their children.

DEFINITIONS

Abuse is defined as acts of commission, neglect as acts of omission. The U.S. government offers a minimal definition of child abuse as "any recent act or failure to act on the part of a parent or caretaker, which results in death, serious physical or emotional harm, sexual abuse or exploitation, or an act or failure to act which presents an imminent risk of serious harm." Many states include other household members and a broader set of circumstances. Children may face situations in which no actual harm has occurred and no imminent risk of serious harm is evident, yet potential harm is a concern. Many states include *potential harm* in their child abuse laws. This is critical to preventing maltreatment, although predicting harm is inherently difficult. Two aspects should be considered: the likelihood and the severity of the potential harm.

Physical abuse includes beating, shaking, burning, drowning, suffocating, and biting. Physical punishment remains controversial, although it is increasingly being prohibited. The Global Initiative to End All Physical Punishment of Children reported that 62 countries have banned physical punishment in all settings, including the home; 135 have done so for schools, and governments in 27 other countries have committed to full prohibition. In the United States, physical punishment in the home remains lawful in all states, and 20 still permit it in schools.

The threshold for when physical punishment should be considered as abuse is unclear. One can consider any injury beyond transient redness such as from a slap as abuse. Proponents of physical punishment suggest that if parents spank a child, it should be limited to the buttocks, be over clothing, and should never involve the head and neck. When parents use objects other than a hand, the potential for serious harm increases. Acts of serious violence (e.g., throwing a hard object, slapping an infant's face) should be seen as abusive even if no injury ensues; significant potential harm exists. Although some PCPs think that hitting is acceptable under limited conditions, almost all prefer more constructive approaches to discipline. The American Academy of Pediatrics issued a policy statement clearly opposing the use of physical punishment. Although many agree that hitting a child should never be accepted, and research has amply documented the potential harm, there remains a reluctance in the United States to label hitting as abuse—unless there is an injury. Clearly the emotional impact of being hit may leave the most worrisome and lasting scars, long after the bruises fade and the fractures heal.

Neglect refers to omissions in care resulting in actual or potential harm. Omissions include inadequate healthcare, education, supervision, or protection from hazards in the environment and unmet physical needs (e.g., clothing, food) and inadequate emotional support. A preferable alternative to focusing on caregiver omissions is to instead consider the *basic needs* (or rights) of children (e.g., adequate food, clothing, shelter, healthcare, education, nurturance). Neglect occurs when a need is not adequately met and results in actual or potential harm, whatever the reasons. A broad definition concerned with children's needs fosters a more comprehensive understanding of what contributes to neglect in addition to the potential parental role. A child-focused definition also offers a more constructive approach to ensure a child's needs are adequately met in contrast to one that narrowly focuses on and blames parents. A child whose health is jeopardized or harmed by not receiving necessary care experiences medical neglect. This view enables professionals to approach the problem in terms of what the child needs, rather than focusing on what parents did badly. Not all such situations necessarily require a referral to child protective services (CPS); less intrusive initial efforts may be appropriate.

Psychologic abuse includes verbal abuse and humiliation and acts that scare or terrorize a child. Although this form of abuse may be extremely harmful to children, resulting in problems such as depression, anxiety, poor self-esteem, and lack of empathy, CPS seldom becomes involved because of the difficulty in proving such allegations. PCPs should still carefully consider this form of maltreatment, even if the concern fails to reach a legal or agency threshold for referral. These children and families can still benefit from counseling and other services. Many children experience more than one form of maltreatment; CPS is more likely to address psychologic abuse in the context of other forms of maltreatment.

INCIDENCE AND PREVALENCE

Abuse and neglect mostly occur behind closed doors and often remain a dark, well-kept secret. Rates of maltreatment are thus difficult to estimate. Nevertheless, the problem is globally prevalent.

Global Situation

The World Health Organization (WHO) estimates that nearly 3 in 4 children, or 300 million children aged 2-4 years, regularly suffer physical punishment and/or psychologic violence at the hands of parents. In addition, as many as 1 in 5 women and 1 in 13 men report having been sexually abused as a child. Less international research has been done on child neglect. Nevertheless, neglect too is clearly a global problem. For example, a large study (n = 41,194) of Balkan countries found lifetime rates of neglect ranging from 23% in Romania to 48% in Bosnia. Among Hong Kong adults, 45% reported a history of childhood neglect. Rates as high as 94% of children for emotional neglect and 89% for physical neglect were found in Burundi, a country severely affected by civil war and political violence. Varying definitions, policies, and practices concerning child maltreatment preclude comparing rates across countries.

United States

There were 4.4 million reports to CPS involving 7.9 million children in the United States in 2019. Of the 656,000 children with substantiated reports (8.9 per 1,000 children), 75% experienced neglect (including 2.3% medical neglect), 17.5% physical abuse, 9.3% sexual abuse, and 6.8% psychologic maltreatment. Neglect is by far the most common form of maltreatment referred to CPS, involving 7 per 1,000 children. Although there had been a welcome decline in rates beginning in the early 1990s, rates increased in 2014 and 2015 and stayed stable until the COVID-19 pandemic, when reports of physical abuse increased. Medical personnel made 11% of all reports. Sources other than official CPS statistics indicate that the incidence of maltreatment is far greater than what gets reported to CPS. In a community survey, for example, 3% of parents reported using very severe violence (e.g., hitting with fist, burning, using gun or knife) toward their child in the prior year.

ETIOLOGY

Child maltreatment seldom has a single cause; rather, multiple and interacting biopsychosocial risk factors at four levels usually interact and contribute to the problem. At the individual level, a child's disability or behavioral challenges or a parent's depression or substance use predispose a child to maltreatment. At the familial level, intimate partner (or domestic) violence jeopardizes children's health and development. Influential community factors include stressors such as dangerous neighborhoods with few supports or recreational facilities. Professional inaction may contribute to neglect, such as when the treatment plan is not clearly communicated or risk factors are ignored. Broad societal factors, such as poverty and its many associated burdens, also contribute significantly to maltreatment. The WHO estimates the rate of child homicide is approximately twofold higher in low-income compared to high-income countries (2.58 vs 1.21 per 100,000 population). Nevertheless, children at all income levels can be maltreated, and PCPs need to guard against biases concerning minoritized and low-income families.

In contrast, protective factors, such as family supports or a parent's concern for their child, may buffer risk factors and protect children from maltreatment. Deliberately identifying and incorporating protective factors is vital to intervening effectively. One can say to a parent who did not fill a prescription, for example, "I can see how much you love [child's name]. What can we do to keep them out of the hospital?" In sum, child maltreatment results from a complex interplay among risk and protective factors. A single parent who has a colicky baby and who recently lost their job has multiple risk factors, but a loving grandparent may be protective. A good assessment and understanding of both risk and protective factors guide an appropriate response.

OUTCOMES

All forms of child maltreatment jeopardize children's physical and emotional health and their cognitive and social development, manifesting in a wide array of possible problems—in the short and the long term. Problems in adolescence and adulthood include health risk behaviors (e.g., smoking, alcohol, and substance use), mental health problems (e.g., anxiety, depression, suicide attempt), and physical health problems (e.g., heart disease, cancer). Maltreated children are also at risk for becoming maltreating parents. The impact of neuroendocrine stress responses to child abuse and neglect on the developing brain may partly explain some of these sequelae.

Some maltreated children appear to be resilient and function relatively well, perhaps owing to protective factors or interventions. Still, PCPs and parents need to be sensitive to the possibility of later problems ("sleeper effects"). The benefits of intervention have been found in even the most severely neglected children, such as those rescued from Romanian orphanages in the early 1990s, who were adopted—the earlier, the better. That said, resilience is a relative concept, and few severely maltreated children escape unscathed.

CLINICAL MANIFESTATIONS

Child abuse and neglect can manifest in a myriad of ways (Table 17.1). A critical element of physical abuse is the lack of a plausible history other than inflicted trauma. The onus is on the clinician to carefully consider the differential diagnosis and not jump to conclusions.

Bruises are the most common manifestation of physical abuse. Features suggestive of abuse include (1) bruising in a preambulatory infant (occurring in just 2% of such infants), (2) bruising of padded and less exposed areas (buttocks, cheeks, ears, neck, genitalia), (3) patterned bruising conforming to the shape of an object (Fig. 17.1), and (4) multiple bruises, especially if clearly of different ages. Earlier suggestions for estimating the age of bruises, however, have long been discredited. It is very difficult to precisely age bruises. The **TEN-4 FACESp** mnemonic is useful for when to suspect abuse in children under 4 years of age: torso, ear, neck, frenulum, angle of jaw, cheeks [fleshy], eyelids, subconjunctivae, and patterned, as well as *any* bruise in children under 4 months, helps identify suspicious bruises. This prediction rule is 95.6% sensitive and 87.1% specific for identifying abuse.

Table 17.1 Injury Patterns

METHOD OF INJURY/ IMPLEMENT	PATTERN OBSERVED
Grip/grab	Relatively round marks that correspond to fingertips and/or thumb
Closed-fist punch	Series of round bruises that correspond to the knuckles of the hand
Slap	Parallel, linear bruises (usually petechial) separated by areas of central sparing
Belt/electrical cord	Loop marks or parallel lines of petechiae (the width of the belt/cord) with central sparing, may see triangular marks from the end of the belt, small circular lesions caused by the holes in the tongue of the belt, and/or a buckle pattern
Rope	Areas of bruising interspersed with areas of abrasion
Other objects/ household implements	Injury in shape of object/implement (e.g., rods, switches, and wires cause linear bruising)
Human bite	Two arches forming a circular or oval shape, may cause bruising and/or abrasion
Strangulation	Petechiae of the head and/or neck, including mucous membranes; may see subconjunctival hemorrhages
Binding/ligature	Marks around the wrists, ankles, or neck; sometimes accompanied by petechiae or edema distal to the ligature mark
Punishment by kneeling on salt or other rough substance	Abrasions/burns, especially to knees
Hair pulling	Traumatic alopecia; may see petechiae on underlying scalp or swelling or tenderness of the scalp (from subgaleal hematoma)
Tattooing or intentional scarring	Abusive cases have been described but can also be a cultural phenomenon (e.g., Māori body ornamentation); may also be a symbol of ownership in a youth being sexually trafficked

In nonmobile infants, bruises are considered a **sentinel injury** because of the low likelihood of noninflicted injury. Bruises are the most common injury to be missed or misdiagnosed among children who later present with fatal or near-fatal injuries. Other sentinel injuries include oropharyngeal injuries in children <6 months of age and subconjunctival hemorrhage in healthy children under 4 years of age.

Conditions such as birthmarks, including slate gray nevus (congenital dermal melanocytosis or Mongolian spots), can be confused with bruises and abuse. Other mimics are noted in Table 17.2. These skin markings are not tender and do not rapidly change color or size. An underlying medical explanation for bruises may exist, such as blood dyscrasias (hemophilia) or connective tissue disorders (Ehlers-Danlos syndrome). The history or examination usually provides clues to these conditions. Hemorrhagic edema of infancy and IgA vasculitis (Henoch-Schönlein purpura) is the most common vasculitis in young

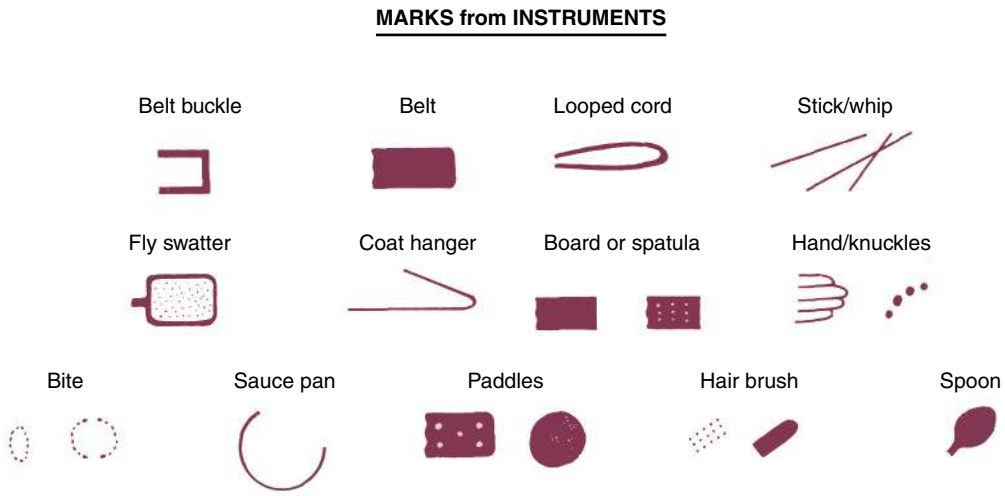

Fig. 17.1 A variety of instruments may be used to inflict injury on a child. Often the choice of an instrument is a matter of convenience. Marks tend to silhouette or outline the shape of the instrument. The possibility of intentional trauma should prompt a high degree of suspicion when injuries to a child are geometric, paired, mirrored, of various ages or types, or on relatively protected parts of the body. Early recognition of intentional trauma is important to provide therapy and prevent escalation to more serious injury.

children, and may be confused with abuse. The pattern and location of bruises caused by abuse are usually different from those caused by a coagulopathy. Noninflicted bruises are characteristically anterior and over bony prominences, such as shins and foreheads. However, the *presence of a medical disorder does not preclude abuse*.

Cultural practices can cause bruising. Cao gio, or coining, is a Southeast Asian folkloric therapy. A hard object is vigorously rubbed on the skin, causing petechiae or purpura. *Cupping* is another approach, popular in the Middle East. A heated glass is applied to the skin, often on the back. As it cools, a vacuum forms, leading to perfectly circular bruises. The context here is important, and such circumstances should not be considered abusive (see Chapter 12).

A careful history of bleeding problems in the patient and first-degree relatives is needed. If a bleeding disorder is suspected, a complete blood count, including platelet count, prothrombin time, and partial thromboplastin time, should be obtained. More extensive testing, such as for factors VIII, IX, and XIII activity and von Willebrand disease, should be considered in consultation with a hematologist.

Bites have a characteristic pattern of one or two opposing arches with multiple bruises. They can be inflicted by an adult, another child, an animal, or the patient. Forensic odontologists developed guidelines for distinguishing adult from child and human from animal bites. However, several recent studies have identified problems with the accuracy and consistency of bite mark analysis.

Burns may be inflicted, noninflicted, or the result of inadequate supervision. Scalding burns may result from immersion or splash. *Immersion burns,* when a child is forcibly held in hot water, show a clear delineation between the burned and healthy skin and uniform depth (Fig. 17.2). They may have a sock or glove distribution. Splash marks are usually absent, unlike when a child inadvertently encounters hot water. Symmetric burns are strongly suggestive of abuse, as are burns of the buttocks and perineum. Although most often noninflicted, splash burns may also result from abuse. Burns from hot objects such as curling irons, radiators, steam irons, metal grids, hot knives, and cigarettes leave patterns indicating the object (Fig. 17.3). A child is likely to try to rapidly escape from a hot object; thus burns that are extensive and deep reflect more than fleeting contact and suggest abuse.

Several conditions mimic abusive burns, such as brushing against a hot radiator, car seat burns, congenital insensitivity to pain syndromes, and folk remedies such as moxibustion. Impetigo may resemble cigarette burns. Cigarette burns are usually 7-10 mm across, whereas impetigo has lesions of varying size. Noninflicted cigarette burns are usually oval and superficial.

Neglect frequently contributes to childhood burns. Children left home alone may be burned in house fires. A parent taking drugs may cause a fire and be unable to protect a child. Exploring children left unattended may pull hot liquids onto themselves. Liquids cool as they flow downward so that the burn is most severe and broad proximally, often in an inverted triangle pattern. If the child is wearing a diaper or clothing, the fabric may absorb the hot water and cause burns worse than otherwise expected. Burns through clothing tend to have an irregular pattern. Some circumstances are difficult to foresee, and a single burn resulting from a momentary lapse in supervision should not automatically be construed as neglect.

Concluding whether a burn was inflicted depends on the history, burn pattern, and the child's capabilities. A delay in seeking healthcare may result from the burn initially appearing minor, before blistering or becoming infected. This circumstance may represent reasonable behavior and should not be automatically deemed neglectful. A scene investigation by law enforcement is often valuable (e.g., testing the water temperature).

Fractures that strongly suggest abuse include those of the posterior ribs, scapula, sternum, and spinous processes and classic metaphyseal lesions—especially in young children (Table 17.3). These fractures all require more force than would be expected from a minor fall or routine handling and activities of a child. Rib and sternal fractures rarely result from cardiopulmonary resuscitation, even when performed by untrained adults. The recommended two-finger or two-thumb technique for infants may, however, produce anterolateral rib fractures. Most common in abused infants are rib (Fig. 17.4), metaphyseal (Fig. 17.5), and skull fractures. Femoral and humeral fractures in nonambulatory infants are also very worrisome for abuse. In contrast, with increasing mobility and running, toddlers can fall with enough rotational force to cause a spiral, femoral fracture. Multiple fractures in various stages of healing are suggestive of abuse. In some circumstances, such as when there are multiple or repeated fractures or a family history of such, underlying medical conditions need to be considered. Clavicular, femoral, supracondylar humeral, and distal extremity fractures in children older than 2 years are most likely noninflicted unless they are multiple or accompanied by other signs of abuse. Few fractures are pathognomonic of abuse; all must be considered together with the history and child's development.

The differential diagnosis includes conditions that increase susceptibility to fractures, such as osteopenia and osteogenesis imperfecta, metabolic and nutritional disorders (e.g., scurvy, rickets), renal osteodystrophy, osteomyelitis, congenital syphilis, and neoplasia (see Table 17.2). Some have pointed to possible rickets and low but subclinical levels of vitamin D as being responsible for fractures thought to be due to abuse. The evidence, however, refutes this supposition. Features of congenital or metabolic conditions

Table 17.2 Mimics of Nonaccidental Trauma

CUTANEOUS LESIONS
Accidental trauma
Congenital coagulation defects (hemophilia, von Willebrand disease)
Acquired coagulation defects (aplastic anemia, ITP, leukemia, vitamin K deficiency)
Ehlers-Danlos syndrome
Vitamin C deficiency
Impetigo
Vasculitis (IgA vasculitis: Henoch-Schönlein purpura)
Dermal melanocytosis (Mongolian spots)
Cupping
Coining
Spooning
SKELETAL LESIONS
Osteogenesis imperfecta
Obstetric trauma
Caffey disease
Rickets (not just low 25-hydroxy-vitamin D levels)
Hyper-IgE syndrome
Recurrent multifocal osteomyelitis
Skeletal dysplasias
HEAD TRAUMA
Birth trauma
Hemophilia
Factor XIII deficiency
Vitamin K deficiency (malabsorption)
Cobalamin C defect
Osteogenesis imperfecta
Ehlers-Danlos syndrome
Glutaric aciduria type I
Menkes syndrome
Vasculitis (primary CNS, systemic)
Benign enlargement of subarachnoid spaces

ITP, Immune thrombocytopenic purpura; IgA, immunoglobulin A; IgE, immunoglobulin E; CNS, central nervous system.

associated with noninflicted fractures include family history of recurrent fractures after minor trauma, abnormally shaped cranium, dentinogenesis imperfecta, blue sclera, impaired hearing, craniotabes, ligamentous laxity, bowed legs, hernia, and translucent skin. *Subperiosteal new bone formation* is a nonspecific finding seen in infectious, traumatic, and metabolic disorders. In young infants, new bone formation may be a normal physiologic finding; it is usually bilateral, symmetric, and less than 2 mm in depth.

The evaluation of a fracture should include a skeletal survey in children less than 24 months of age when abuse seems possible (Table 17.4). Multiple radiographs with different views are needed; "babygrams" (one or two films of the entire body) should be avoided. If a fracture is found or when the survey is normal but concern for an occult injury remains, a follow-up survey should be completed 2 weeks later, as it may reveal fractures not apparent initially. Omission of skull, spine, and pelvis films on repeat survey reduces radiation exposure while still capturing most occult fractures.

In corroborating the history and the injury, the age of a fracture can be crudely estimated (Table 17.5). Soft tissue swelling subsides in 2-21 days. Subperiosteal new bone is visible within 4-21 days. Loss of definition of the fracture line and visible soft callus formation occur on a similar timeline. Hard callus is visible between 14 and 90 days. These ranges are shorter in infancy and longer in children with poor nutritional status or a chronic underlying disease. Fractures of flat bones such as the skull do not form a callus and cannot be aged, although soft tissue swelling indicates recency (i.e., within the prior week).

Abusive head trauma (AHT) results in significant morbidity and mortality. Abusive injury may be caused by direct impact, asphyxia, shaking, or a combination. Subdural hematomas (Fig. 17.6); retinal hemorrhages, especially when extensive and involving multiple layers; brain parenchymal injury; and fractures (often rib and classic metaphyseal lesions) strongly suggest AHT, especially when they occur together. Infants' poor neck muscle tone and relatively large heads make them vulnerable to acceleration-deceleration forces if severely shaken, leading to AHT. Children may lack external signs of injury, even with serious intracranial trauma. The clinical presentation varies, ranging from nonspecific lethargy, to vomiting (without diarrhea), changing neurologic status or seizures, or coma. In all preverbal children, the possibility of AHT should be considered when children present with these signs or symptoms.

Acute intracranial trauma is best evaluated via CT. CT helps identify bone and soft tissue injury. Some centers use fast-sequence MRI to reduce radiation exposure, but the sensitivity may not be as good as CT. MRIs are helpful in differentiating extraaxial fluid, determining the approximate time of injuries, assessing parenchymal injury, and identifying vascular anomalies. Neck imaging may identify spinal subdural blood and ligamentous, spinal cord, and nerve root injuries. MRIs are best obtained 5-7 days after an acute injury. Other causes of subdural hemorrhage in infants include arteriovenous malformations, coagulopathies, birth trauma, tumor, and infections (see Table 17.2). Glutaric aciduria type 1 can present with intracranial bleeding and should be considered. When AHT is suspected, possible injuries elsewhere—especially skeletal and abdominal—should be ruled out.

Retinal hemorrhages are an important marker of AHT (Fig. 17.7). Whenever AHT is being considered, a dilated indirect eye examination by a pediatric ophthalmologist should be performed. Although retinal hemorrhages can be found in other conditions, hemorrhages that are multiple, involve more than one retinal layer, and extend to the periphery are very suspicious for abuse. The mechanism is likely repeated acceleration-deceleration caused by shaking. Traumatic retinoschisis points strongly to abuse.

With other causes of retinal hemorrhages, the pattern is usually different from that seen in child abuse. After birth, many newborns have them, but they disappear by 2-6 weeks. Coagulopathies (particularly leukemia), retinal diseases, carbon monoxide poisoning, and glutaric aciduria may be responsible. Severe noninflicted direct crush injury to the head can rarely cause an extensive hemorrhagic retinopathy. Cardiopulmonary resuscitation rarely, if ever, causes retinal hemorrhages in infants and children; if present, there are only a few hemorrhages in the posterior pole. Hemoglobinopathies, diabetes mellitus, routine play, minor noninflicted head trauma, and vaccinations do not appear to cause retinal hemorrhage in children. Severe coughing or seizures rarely cause retinal hemorrhages that could be confused with AHT.

The dilemma frequently posed is whether minor, everyday forces can explain the findings seen in AHT. Simple linear skull fractures in the absence of other suggestive evidence can be explained by a short fall, although even that is unusual (1–2%); underlying brain injury from short falls is exceedingly rare. Timing of brain injuries in cases of abuse is not precise. In fatal cases, however, the trauma most likely occurred very soon before the child became symptomatic.

Other manifestations of AHT may be seen. *Raccoon eyes* are associated with subgaleal hematomas after traction on the anterior hair and scalp or a blow to the forehead. Neuroblastoma can present similarly. Bruises from attempted strangulation may be visible on the neck. Choking or suffocation can cause hypoxic brain injury, often with no external signs.

Oral lesions may present as bruised lips, bleeding, torn frenulum, and dental trauma or multiple caries (neglect).

Abdominal trauma also accounts for significant morbidity and mortality in abused children. Young children are especially vulnerable because of their relatively large abdomens and lax abdominal musculature. A forceful blow or kick can cause hematomas of solid organs (liver, spleen, kidney) from compression against the spine, as well as hematomas (duodenal) or rupture (stomach) of hollow organs. Intra-abdominal bleeding may result from trauma to an organ or from

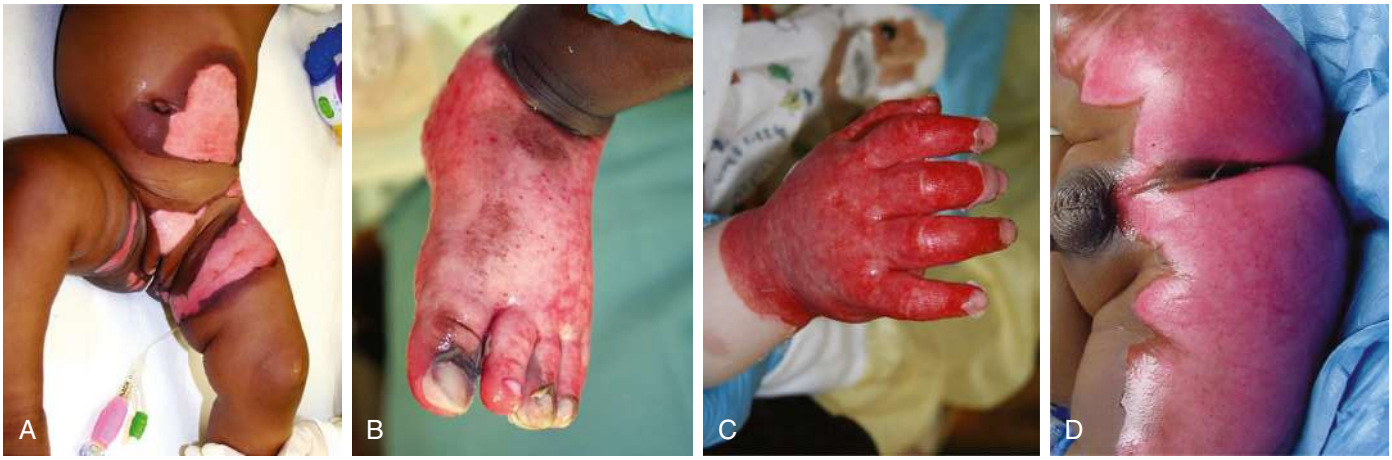

Fig. 17.2 Immersion injury patterns. A, Sparing of flexural creases. B, Immersion "sock" burn. C, Immersion "glove" burn. D, Immersion buttocks burn. *(From Jenny C. Child abuse and neglect: diagnosis, treatment, and evidence. Philadelphia: Saunders;2011: Fig. 28-3, p. 225.)*

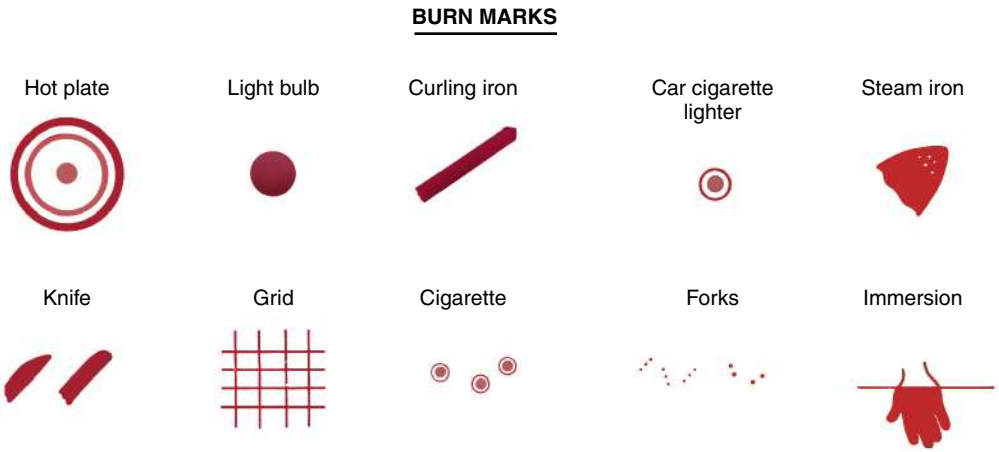

Fig. 17.3 Marks from heated objects cause burns in a pattern that duplicates that of the object. Familiarity with the common heated objects that are used to traumatize children facilitates recognition of possible intentional injuries. The location of the burn is important in determining its cause. Children tend to explore surfaces with the palmar surface of the hand and rarely touch a heated object repeatedly or for a long time.

Table 17.3 Specificity of Radiologic Findings

HIGH SPECIFICITY*
Classic metaphyseal lesions
Rib fractures, especially posteromedial
Scapular fractures
Spinous process fractures
Sternal fractures
MODERATE SPECIFICITY
Multiple fractures, especially bilateral
Fractures of different ages
Epiphyseal separations
Vertebral body fractures and subluxations
Digital fractures
Complex skull fractures
Pelvic fractures
COMMON BUT LOW SPECIFICITY
Subperiosteal new bone formation
Clavicular fractures
Long bone shaft fractures
Linear skull fractures

*Highest specificity applies in infants
From Kleinman PK. *Diagnostic imaging of child abuse,* 3rd ed. Cambridge, UK: Cambridge University Press;2015: 24.

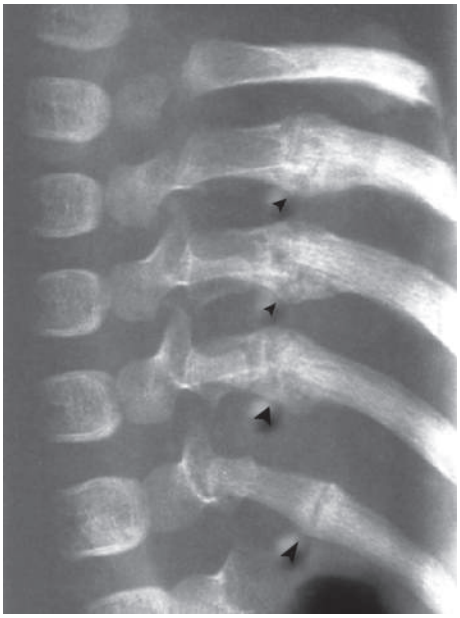

Fig. 17.4 High detail oblique view of the ribs of a 6-month-old infant shows multiple healing posteromedial rib fractures *(arrowheads).* The level of detail in the image is far greater that what would be present on a standard chest radiograph. *(From Dwek JR. The radiographic approach to child abuse. Clin Orthop Relat Res. 2011;469:776–789, Fig. 4.)*

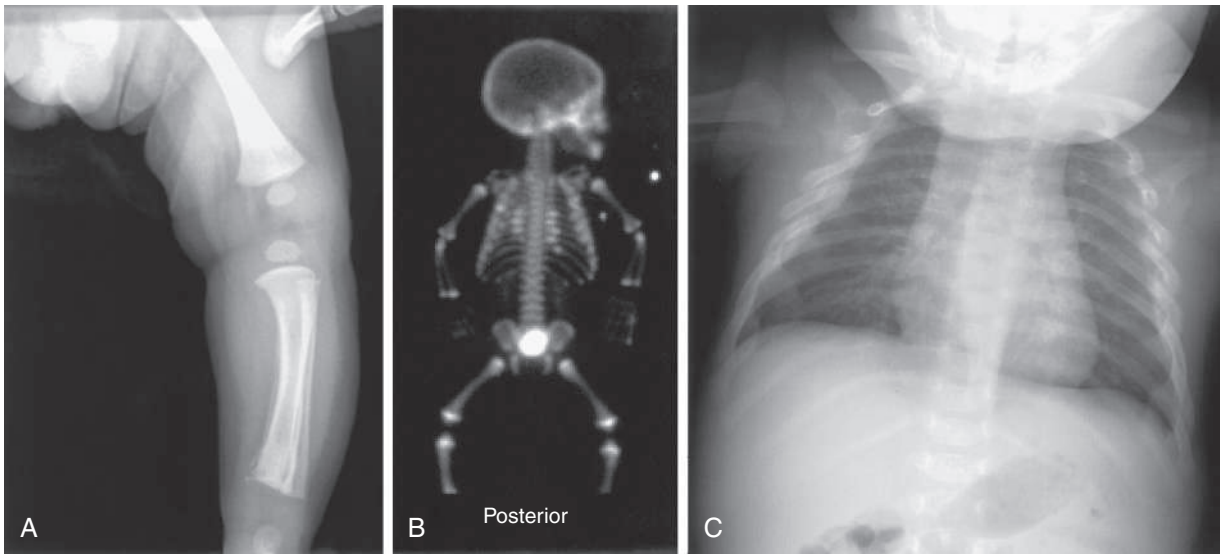

Fig. 17.5 **A,** Metaphyseal fracture of the distal tibia in a 3-month-old infant admitted to the hospital with severe head injury. There is also periosteal new bone formation of the tibia, perhaps from previous injury. **B,** Bone scan of the same infant. The initial chest x-ray showed a single fracture of the right posterior fourth rib. A radionuclide bone scan performed 2 days later revealed multiple previously unrecognized fractures of the posterior and lateral ribs. **C,** Follow-up radiograph 2 weeks later showed multiple healing rib fractures. This pattern of fractures is highly specific for child abuse. The mechanism of these injuries is usually violent squeezing of the chest.

Table 17.4 Radiologic Skeletal Survey for Infants and Children under 2 Years of Age*

- Anteroposterior (AP) and lateral views of skull (Townes view optional; add if any fracture seen)
- Lateral spine (cervical spine [C-spine] may be included on skull radiographs; AP spine is included on AP chest and AP pelvis views to include entire spine)
- AP view, right posterior oblique, left posterior oblique view of chest-rib technique
- AP pelvis
- AP view of each femur
- AP view of each leg
- AP view of each humerus
- AP view of each forearm
- Posteroanterior (PA) view of each hand
- AP (dorsoventral) view of each foot

*Images are checked by a radiologist before the patient leaves. Poorly positioned or otherwise suboptimal images should be repeated. Lateral views are added for positive or equivocal findings in the extremities. Coned views of positive or equivocal findings (i.e., at ends of long bones, ribs) may be obtained.
Adapted from Coley BD. *Caffey's pediatric diagnostic imaging*, 12th ed. Philadelphia: Mosby;2013: Box 144-1, p. 1588.

Table 17.5 Timetable of Radiologic Changes in Children's Fractures*

CATEGORY	EARLY	PEAK	LATE
1. SPNBF	4-10 days	10-14 days	14-21 days
2. Loss of fracture line definition, days		10-14 days	14-21 days
3. Soft callus		10-14 days	14-21 days
4. Hard callus	14-21 days	21-42 days	42-90 days

The time points tend to increase from early infancy into childhood.
*Repetitive injuries may prolong all categories.
SPNBF, Subperiosteal new bone formation.
From Kleinman PK. *Diagnostic imaging of child abuse*, 3rd ed. Cambridge, UK: Cambridge University Press;2015: p. 215.

shearing of a vessel. More than one organ may be affected. Children may present with cardiovascular failure or an acute abdomen, often after a delay in care. Bilious vomiting without fever or peritoneal irritation suggests a duodenal hematoma, often the result of abuse.

The manifestations of abdominal trauma are often subtle, even with severe injuries. Bruising of the abdominal wall is unusual, and symptoms may evolve slowly. Delayed perforation may occur days after the injury; bowel strictures or a pancreatic pseudocyst can develop weeks or months later. PCPs should consider screening for occult abdominal trauma when other evidence of physical abuse exists. Screening should include liver and pancreatic enzyme levels and testing urine for blood. When results indicate possible injury or if there is concern about possible splenic, adrenal, or hepatic injury, an abdominal CT is indicated.

Neglect is the most prevalent form of child maltreatment, with potentially severe and lasting sequelae. It may manifest in many ways, depending on which basic needs are not adequately met. Nonadherence to medical treatment, for example, may aggravate the condition, as may a delay in seeking healthcare. Inadequate food may manifest as impaired growth; inattention to obesity is also a problem. Poor hygiene may contribute to infected cuts or lesions. Inadequate supervision contributes to injuries and ingestions. Children's needs for mental healthcare, dental care, and other healthcare may be inadequately met, manifesting as neglect. Educational needs, particularly for children with learning disabilities, are often not adequately met.

GENERAL PRINCIPLES FOR ASSESSING POSSIBLE PHYSICAL ABUSE AND NEGLECT

The heterogeneity of circumstances in situations of child maltreatment precludes specific detailing of varied assessments. The following are useful general principles:

- Given the complexity and possible ramifications of determining child maltreatment, an **interdisciplinary assessment** is optimal, with input from all involved professionals. Consultation with a physician expert in child abuse pediatrics is recommended.
- A thorough **history** should be obtained from the parent(s), optimally via separate interviews.
- Verbal children should be interviewed separately in a developmentally appropriate manner. **Open-ended questions** (e.g., "Tell me what happened") are best. Some children need more directed

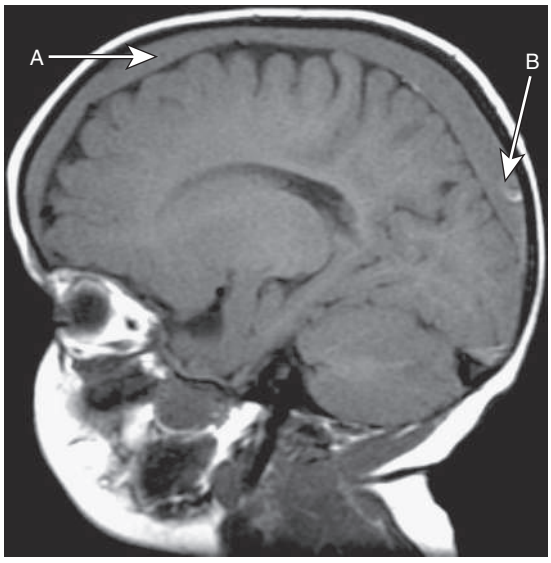

Fig. 17.6 CT scan indicating intracranial bleeding. *A*, Older blood. *B*, New blood.

questioning (e.g., "How did you get that bruise?"); others need multiple-choice questions. Leading questions must be avoided (e.g., "Did your daddy hit you?").

- A thorough **physical examination** is necessary.
- Careful **documentation** of the history and physical is essential. Verbatim quotes are valuable, including the question that prompted the response. Photographs are helpful.
- For **abuse**, the assessment should answer these questions: What is the evidence for concluding abuse? Have other diagnoses been ruled out? What is the likely mechanism of the injury? When did the injury likely occur?
- For **neglect**, the assessment should answer these questions: Do the circumstances indicate that the child's needs have not been adequately met? Is there evidence of actual harm? Is there evidence of potential harm and on what basis? Suboptimal treatment adherence may not be ideal but lead to few or no consequences. What is the nature of the neglect? Is there a pattern of neglect?
- It may be **difficult to be certain** regarding the likelihood of abuse or neglect. The use of "possible" or "probable" is recommended when uncertain. Inadequacies in the care children receive naturally fall along a continuum, requiring a range of responses tailored to the individual family's situation. Legal considerations or CPS practice may discourage PCPs from labeling many circumstances as neglect. Even if neglect does not meet a threshold for referring to CPS, professionals can still help ensure children's needs are adequately met.
- Are there indications of **other forms of maltreatment**? Has there been prior CPS involvement?
- A child's **safety** is a paramount concern. What is the risk of imminent harm and of what severity?
- What is contributing to the maltreatment? Consider the categories described in the section on etiology.
- What **strengths/resources** are there? This is as important as identifying problems.
- What **treatment or services** do the child and family need? What interventions have been tried and with what results? Knowing the nature of these interventions can be useful, especially from the parent's perspective.
- What is the **prognosis**? Is the family motivated to improve the circumstances and accept help, or are they resistant? Are needed resources, formal and informal, available?
- Are there **other children** in the home who should be assessed for maltreatment?

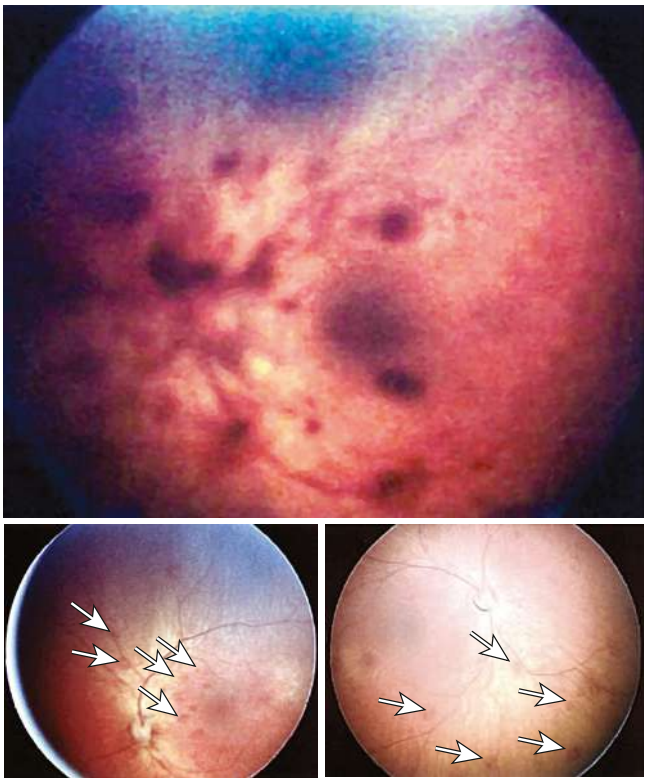

Fig. 17.7 Retinal hemorrhages. *Arrows* point to hemorrhages of varying sizes.

GENERAL PRINCIPLES FOR ADDRESSING PHYSICAL ABUSE AND NEGLECT

The heterogeneity of circumstances also precludes specific details regarding how to address different types of maltreatment. The following are general principles:

- Treat any medical problems.
- Help ensure the child's safety, often in conjunction with CPS; this is a priority. In some instances, hospitalization is the prudent approach.
- Convey concerns of maltreatment to parents, kindly but forthrightly. Avoid blaming. It is natural to feel anger towards parents of maltreated children, but they need support and deserve respect.
- Have a means of addressing the difficult emotions child maltreatment can evoke in us. Self-care is important.
- Be empathic and state interest in helping or suggest another healthcare professional.
- Know the laws and/or local CPS policies on referring child maltreatment. In the United States, the legal threshold for referring is typically "reason to believe" (or "reason to suspect"); one does not need to be certain. Physical abuse and moderate to severe neglect warrant a referral. In less severe neglect, less intrusive interventions may be an appropriate initial response. For example, if an infant's mild failure to gain sufficient weight is caused by an error in mixing the formula, parent education and perhaps a visiting nurse should be tried. In contrast, severe growth faltering may require hospitalization, and, if the contributing factors are particularly serious (e.g., a psychotic mother), out-of-home placement may be needed. CPS can assess the home environment and provide valuable insights.
- Referring child maltreatment to public agencies is never easy. Parental inadequacy or culpability is at least implicit, and parents may become angry. PCPs should supportively inform families directly of the referral to CPS; it can be explained constructively as an effort to clarify the situation and provide help, as well as a professional (and legal) responsibility. Words matter, and "referral" avoids the stigma of "report," and it is what we commonly

do in healthcare. Explaining what the ensuing process is likely to entail (e.g., a visit from a CPS worker and sometimes a police officer) may ease a parent's anxiety. Parents are frequently concerned that they might lose their child. PCPs can cautiously reassure parents that CPS is responsible for helping children and families and that, in most instances, children remain with their parents. When CPS does not accept a referral or when it is not substantiated, they may still facilitate supportive services such as food, shelter, parenting resources, and childcare. PCPs can be a useful liaison between the family and the public agencies and should try to remain involved after referring to CPS.

- Help address contributory factors, prioritizing those that are most important to the family and amenable to being remedied. Concrete needs should not be overlooked; accessing food programs, obtaining health insurance, enrolling children in preschool, and help finding housing can make a valuable difference. Parents may need their own problems addressed to enable them to adequately care for their children.
- Establish specific objectives (e.g., no hitting, diabetes will be adequately controlled), with measurable outcomes (e.g., urine dipsticks, hemoglobin A_{1c}). Similarly, advice should be specific and limited to a few reasonable steps. A written (and perhaps signed) contract can help establish the agreed-upon plan and help ensure it pans out.
- Engage the family in developing the plan—solicit their input and agreement. Motivational interviewing (MI) offers a fundamentally different approach to working with parents (and older children and teens), forging a partnership, and understanding their perceptions of an issue and how they think they can address it. Knowledge and skills regarding MI can enhance the effectiveness of PCPs (see Chapter 18).
- Deliberately identify protective factors or strengths—within and outside the family; there are always some. Incorporating these in one's approach is a valuable way to engage parents and ensure plans get implemented.
- Encourage informal supports (e.g., family, friends; invite fathers to office visits). This is where most people get their support, not from professionals. Consider support available through a family's religious affiliation.
- Consider children's specific needs. Too often, maltreated children do not receive needed services.
- Be knowledgeable about community resources and facilitate appropriate referrals. Consider how to help ensure referrals pan out.
- Provide support, follow-up, and review of progress, and adjust the plan if needed.
- Recognize that maltreatment often requires long-term intervention with ongoing support and monitoring.

PREVENTION OF PHYSICAL ABUSE AND NEGLECT

An important aspect of prevention is that many of the efforts to strengthen families and support parents should promote children's health, development, well-being, and safety and prevent maltreatment. Medical responses to child maltreatment have typically occurred after the fact; preventing the problem is preferable. PCPs can help in several ways. An ongoing relationship offers opportunities to develop trust and knowledge of a family's circumstances. Astute observation of parent–child interactions can reveal useful information.

Parent and child education regarding medical conditions helps to ensure implementation of the treatment plan and to prevent neglect. Possible barriers to treatment should be addressed. Practical strategies such as writing down the plan can help. In addition, anticipatory guidance helps with positive parenting (see Chapter 20), diminishing the risk of maltreatment. Hospital-based programs that educate parents about caring for a crying infant and the risks of shaking may help prevent AHT.

Screening for and addressing major psychosocial risk factors for maltreatment such as parental depression, substance use, intimate partner violence, major stress, and helping address identified problems, often via referrals, can help prevent maltreatment. Primary care offers excellent opportunities to screen briefly for psychosocial problems. The traditional organ system–focused review of systems can be expanded to probe areas such as feelings about the child, the parent's own functioning, the relationship, possible depression, disciplinary approaches, stressors, and supports. The Safe Environment for Every Kid (SEEK) model offers an evidence-informed approach for pediatric primary care to identify and help address prevalent adverse childhood experiences (ACEs) (e.g., exposure to intimate partner violence, parental depression, or substance use) or social determinants of health (e.g., food insecurity, severe parental stress) that are also risk factors for child maltreatment. This approach should incorporate working with protective factors and use of MI principles in developing a plan jointly with the family.

Obtaining information directly from children or youth is also important, especially given that separate interviews with teens have become the norm. Any concerns identified on such screens require at least a brief assessment and initial management, which may lead to a referral for further evaluation and treatment. More frequent office visits can be scheduled for support and counseling while monitoring the situation. Other key family members (e.g., father, a grandparent) might be invited to participate, thereby encouraging informal support. Some practices arrange parent groups through which problems and solutions are shared. PCPs also need to recognize their limitations and facilitate referrals to other community resources.

ADVOCACY

PCPs can assist in understanding what contributed to a child's maltreatment. When advocating for the best interest of the child and family, addressing contributory factors at the individual, family, and community levels is optimal. At the individual level, an example of advocating on behalf of a child is explaining to a parent that an active toddler is behaving normally and not intentionally annoying the parent. Encouraging a parent to seek help dealing with a violent spouse, saying, for example, "You and your life are very important"; asking about substance use; and helping parents obtain health insurance for their children are all forms of advocacy.

Efforts to improve family functioning, such as encouraging fathers' involvement in the lives of their children, are also examples of advocacy. Remaining involved after a referral to CPS and helping ensure needed services are provided is advocacy as well. In the community, PCPs can be influential advocates for improving resources devoted to children and families. These include parenting programs, services for abused women and children, and recreational facilities. They can be strong advocates for policies and programs at the local, state, and national levels to benefit children and families. The problems underpinning child maltreatment, such as poverty, parental stress, substance use, and limited child-rearing resources, require policies and programs that enhance families' abilities to care for their children at least adequately. Examples in the United States include Medicaid, the Supplemental Nutrition Assistance Program (SNAP), the Women, Infants, and Children (WIC) program, paid family and medical leave, the Earned Income Tax Credit (EITC), and childcare subsidies.

Child maltreatment is a complex problem without simple solutions. Through partnerships with parents and colleagues in child protection, mental health, education, and law enforcement, PCPs can make an enormous difference in the lives of many children and families.

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17.1 Sexual Abuse

Wendy G. Lane and Howard Dubowitz

See also Chapter 162.

Approximately 18% of females and 7% of males in the United States are sexually abused at some point during childhood. Primary care professionals (PCPs) serving children can play several roles in addressing sexual abuse, including identification, referring to child protective services (CPS) and/or law enforcement, testing for and treating sexually transmitted infections, providing support and reassurance, and providing guidance to prevent future sexual abuse. In many jurisdictions throughout the United States, PCPs play a mostly triage role, with the definitive medical evaluation conducted by a child abuse specialist.

DEFINITION

Sexual abuse has been defined as "the involvement of dependent, developmentally immature children and adolescents in sexual activities which they do not fully comprehend, to which they are unable to give consent, or that violate the social taboos of family roles." Sexual abuse includes exposure to sexually explicit materials, oral-genital contact, genital-to-genital contact, genital-to-anal contact, and genital fondling. Any touching of "private parts" by parents or caregivers in a context other than necessary care is inappropriate. It is important to note that sexual abuse does not have to involve direct touching or physical contact by the perpetrator. Showing pornography to a child, filming or photographing a child in sexually explicit poses, and encouraging or forcing a child to perform sex acts on another all constitute sexual abuse. When these acts occur for financial gain or in exchange for something of value, it is considered sexual exploitation. Recruiting, enticing, harboring, transporting, providing, obtaining, and/or maintaining a minor for the purpose of engaging in sexual acts are forms of sex trafficking (see Chapter 16), a subset of sexual exploitation.

Some legal definitions distinguish sexual abuse from sexual assault; the former being committed by a parent or caregiver or household member, and the latter being committed by someone without a custodial or any relationship to the child. For this chapter, the term *sexual abuse* encompasses abuse, assault, and exploitation.

PRESENTATION OF SEXUAL ABUSE

Because physical findings are uncommon and behavioral findings are often nonspecific, a more reliable means of identifying sexual abuse is through a child's history. Some children provide a clear, spontaneous description of abuse to a trusted adult. Other children provide less clear histories, such as not wanting to visit a particular person's home or vaguely saying "something bad happened." Preschool-aged children and those with limited language skills may be developmentally unable to provide details about sexual acts or timing. Such lack of detail may unfortunately dissuade adults from trusting the account and referring. Because PCPs are mandated reporters, they should have a low threshold for referring young children.

Sexual abuse may be discovered when another person witnesses the abuse or discovers evidence such as sexually explicit photographs or videos. There are also children, with and without symptoms, who will not be identified at any point during their childhood, and perhaps never.

Behavioral changes may be the first indication of possible abuse. Children may exhibit **sexually explicit behavior** outside the norm for their age and developmental level. It can be tricky to distinguish normal from concerning behavior, especially given children's increasing and prevalent exposure to sexual material and information over recent decades. For preschool- and school-age children, behavior thought to be normal includes curiosity about their own body and differences between boys and girls. Touching their own genitals, masturbation, and undressing in front of others are also common. Worrisome sexual behavior includes compulsive masturbation (i.e., continuing in public areas even after being told to stop), attempting to perform sex acts on adults or other children, or asking adults or children to perform sex acts on them. Teen sexual behavior thought to be normal includes interest in media with sexual themes, looking up sexual information on the internet, demanding more privacy, masturbation, and sexual contact with teens of the same or opposite sex. Worrisome teenage behaviors include sexual promiscuity, engaging in prostitution, and engaging in sexual acts with younger children or with animals. Sexting has become common among teenagers and requires a discussion between parents and teens about its risks. Sexting that involves extortion or trafficking is very concerning; in many states trafficking requires mandated reporting to CPS.

It is important to recognize that in addition to sexual abuse, some sexualized behavior could also result from other exposure (e.g., a child who enters their parents' bedroom at night to find their parents having sex), from neglect (e.g., parents watching pornographic movies where a child can see them), from exposure to sexual behavior by other children who may have been abused or exposed to inappropriate sexual behavior or materials, or from information discussed and shared by peers.

A number of other behavior changes, although not specific for sexual abuse, are common among children who have been sexually abused. These include social withdrawal, acting out, increased clinginess or fearfulness, distractibility, learning difficulties, and behavioral regression such as secondary enuresis. Teenagers may become depressed, experiment with drugs or alcohol, or run away from home. Therefore sexual abuse should usually be considered when addressing a wide variety of child behavior and mental health problems.

Physical signs of sexual abuse are uncommon and are seen in only about 5% of children who undergo medical examination, usually soon after the abuse occurred. The absence of physical findings can often be explained by the type and timing of sexual contact. Abusive acts such as fondling or even digital penetration may not cause any injury. In addition, many children do not disclose abuse until days, weeks, months, or even years after the abuse occurred. Because genital injuries usually heal within days, injuries are generally not seen by the time a child presents for medical evaluation. Clearly, a normal genital exam does not rule out the possibility or probability of abuse and should not influence the decision to refer to CPS. Physical findings that may indicate sexual abuse include genital or anal pain, anogenital bleeding, or discharge. Sexually transmitted infections (STIs), including gonorrhea, chlamydia, and trichomonas beyond the neonatal period, are highly suspicious for abuse. Pregnancy, too, may be the result of abuse. Rarely, there are physical signs of healed trauma, such as a complete hymenal transection (i.e., part of the posterior hymen is missing).

All 50 U.S. states mandate that professionals refer suspected sexual abuse to CPS, and many require reporting of sex trafficking. The specific criteria or threshold for "reason to suspect" is generally not defined by state law. Clearly, referrals do not require certainty that abuse occurred. Therefore it may be appropriate to refer a child with worrisome sexual behavior when no alternative explanation is plausible and the child does not clearly confirm or deny abuse.

THE ROLE OF THE PCP IN ASSESSING AND ADDRESSING POSSIBLE SEXUAL ABUSE

Speaking with parents about possible abuse: When a parent raises concern for sexual abuse, PCPs should have the child leave the room before obtaining additional information from the parent alone to avoid influencing the child. The child healthcare professional should gather details regarding the parent's concern to help discriminate between possible sexual abuse and other behavioral or health issues. For example, parents may be worried about a child's normal sexual behavior, or they may assume that a nonspecific finding such as vulvar irritation is the result of abuse. In these situations, reassurance and treatment

of the medical issue may suffice. PCPs should document the parental concerns, clearly indicating the source of the information. If a child reported abuse to a parent, documentation should include what questions the parent asked to elicit the disclosure or what triggered it. Additional evaluation should include a review of systems for behavioral and urogenital problems. Parents should be asked whether there are other children in the home, school, or childcare who may have been exposed to the alleged offender; this information should be shared with CPS, as these children may benefit from a precautionary interview or exam at the local child advocacy center (CAC). Parents who have experienced sexual abuse themselves may disclose this information to the child healthcare professional, and they may have a heightened concern about abuse of their children and the sequelae. In these situations, the PCP should discuss mental health services for the parent. Some states require reporting of sexual abuse even when the survivor is an adult.

Speaking with children about possible abuse: Children with suspected sexual abuse may present to the PCP's office with a clear history of abuse or more subtle indicators. A private, brief conversation between PCP and child provides an opportunity for the child to speak in their own words. Doing this may be especially important when the parent does not believe or support the child. Telling parents that a private conversation is standard in such circumstances can be reassuring.

When speaking with a child, it is essential to **first establish rapport**, starting with general and open-ended questions; for example: "Tell me about school" and "What are your favorite things to do?" It helps to explain the purpose of the evaluation and why it is being done. For example, "Your mom is worried that someone may have hurt you and we want to make sure you're healthy and safe." Questions about sexual abuse should focus on **a minimally adequate history** (i.e., gathering enough information to determine if sexual abuse may have happened and whether there is a need to refer to CPS). If a referral is made to CPS, a multidisciplinary investigation will likely be initiated, including an extensive forensic interview. Questions should also be nonleading (e.g., avoid asking questions such as "who touched you there?"). It helps to explain that sometimes children are hurt or bothered by others and that one wonders whether that might have happened to the child. Open-ended questions, such as "Can you tell me more about that?" allow the child to add information and clarification in their own words. The PCP should document the child's statements in quotation marks and the source. Documenting the questions that elicited the child's response should clarify whether questions were leading or not. Very young children and those with developmental delay may lack the verbal skills to describe what happened. In this situation, the parent's history may provide enough information to warrant a CPS referral without interviewing the child.

Medical referral: Because delayed disclosure is common, most children do not need an urgent expert medical evaluation (Fig. 17.8). Indications for one include recent abuse (i.e., within the past 3-5 days), current pain or bleeding, and severe child or parental emotional distress. It is optimal for children suspected of having been sexually abused to be evaluated in a child-friendly setting and by professionals skilled in this field. Because emergency departments may not have a child abuse expert and can be busy, noisy, and lacking in privacy, examination at an alternative location such as a CAC or outpatient clinic is preferable, when possible. If the exam is not urgent, it is best that the evaluation be done at a time when the child is not tired and cranky.

Referring PCPs should be familiar with the triage procedures in their communities, including the referral sites for both acute and nonacute evaluations, timeframes for when an evaluation is considered acute, and whether there are different referral sites for prepubertal and postpubertal children. Depending on the jurisdiction, the site may be an emergency department, a CAC, or an outpatient clinic. For the *prepubertal child,* if abuse is thought to have occurred in the previous 72 hours and history suggests direct contact, forensic evidence collection (e.g., external genital, vaginal, anal, and oral swabs, sometimes referred to as a *rape kit*) may be indicated, and the

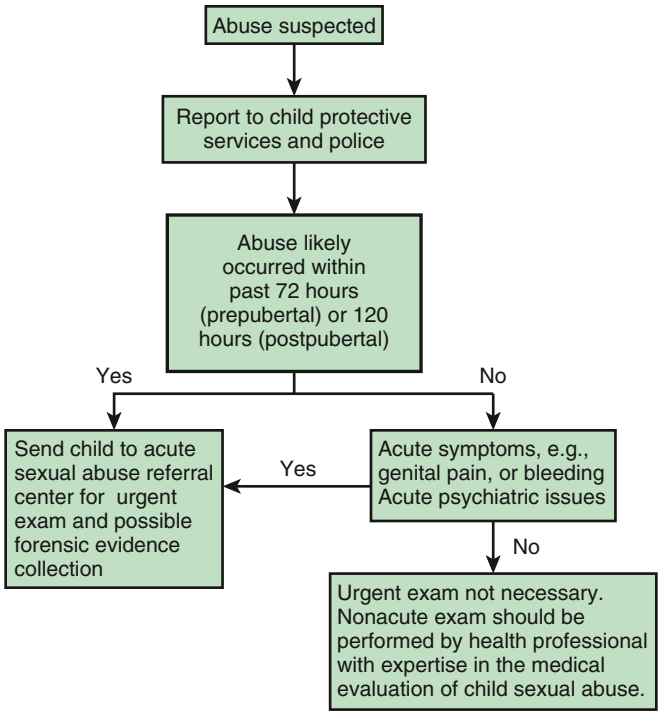

Fig. 17.8 Triage protocol for children with suspected sexual abuse.

child should be referred to a site equipped to do this. Some centers may have shorter or longer cutoffs (e.g., 24 hours or 5 days). If the last suspected incident of abuse occurred more than 72 hours prior, the likelihood of recovering forensic evidence is extremely low, making forensic evidence collection unnecessary. For *postpubertal females,* it is recommended that forensic evidence be collected up to 120 hours after the abuse—as for adult women. The extended timeframe relates to semen possibly remaining in the postpubertal vaginal vault for more than 72 hours. Some jurisdictions extend the time for collecting forensic evidence up to 10-15 days if there has been penetration and possible ejaculation. The National Institute of Justice suggests considering a 9-day time frame based on one study.

Physical examination of the child with suspected sexual abuse: Children suspected of having been sexually abused may benefit from a brief evaluation and examination of their anogenital area to determine whether and when an expert medical evaluation is needed. Unfortunately, many physicians are unfamiliar with genital anatomy, particularly in the prepubertal girl (Figs. 17.9 and 17.10). Nevertheless, signs of trauma such as bruising, abrasions, and bleeding or of infection may be apparent. Because about 95% of children who undergo a medical evaluation after sexual abuse have normal exams, the role of the PCP is often simply to be able to distinguish a normal exam from findings indicative of common medical concerns (e.g., diaper dermatitis) or trauma, or to reassure a parent whose preschooler is touching themself. Unsuspected injuries or medical problems such as labial adhesions, imperforate hymen, or urethral prolapse may be identified. In addition, reassurance about the child's physical health may often allay anxiety for the child and family.

When concerns about sexual abuse arise because of genital findings or complaints, it is important to assess for and rule out medical problems that can be confused with abuse. Several genital findings may raise concern about abuse but often have alternative explanations. For example, genital redness in a prepubertal child is usually caused by nonspecific vulvovaginitis, diaper dermatitis, or infection with a nonsexually transmitted organism such as staphylococcus or

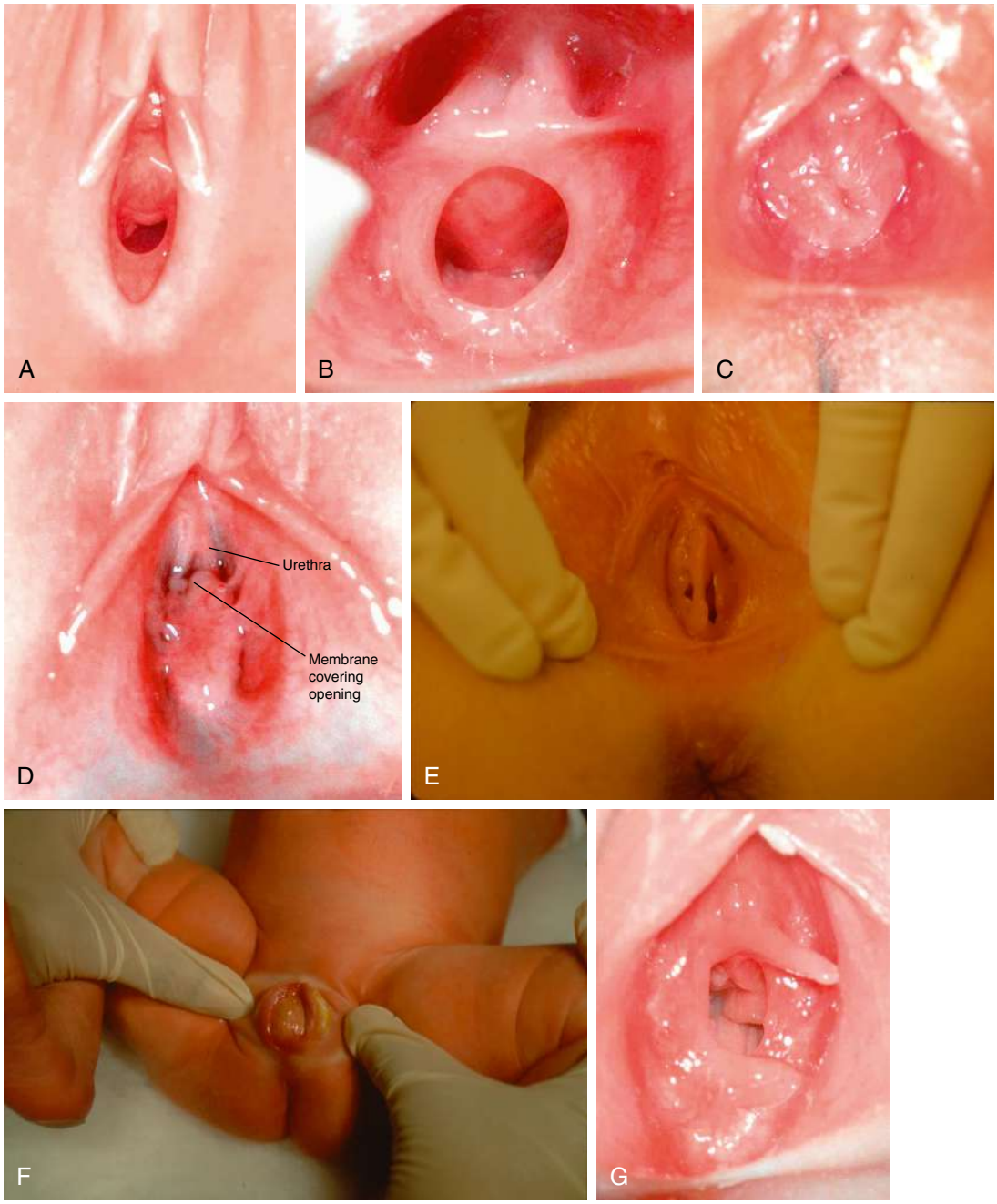

Fig. 17.9 Types of hymens. **A,** Crescentic. **B,** Annular. **C,** Redundant. **D,** Microperforate. **E,** Septated. **F,** Imperforate. **G,** Hymeneal tags. *(A-D and G from McCann JJ, Kerns DL. The Anatomy of Child and Adolescent Sexual Abuse. St. Louis: InterCorp, 1999; E and F from Perlman SE, Nakajima ST, Hertweck SP. Clinical Protocols in Pediatric and Adolescent Gynecology. London: Parthenon Publishing Group, 2004. Figs. 25.5 and 25.9.)*

group A streptococcus. It is often apparent that the diffuse redness is unlikely to be the result of trauma. Lichen sclerosis is an uncommon cause of redness and usually presents with vulvar and/or perianal atrophy and hypopigmentation, often in a figure 8 pattern. Vaginal discharge can be caused by STIs, but also by poor hygiene, foreign body, the onset of puberty, or infection with *Salmonella, Shigella,* or *Yersinia*. Genital ulcers can be caused by herpes simplex virus (HSV) and syphilis, but also by Epstein-Barr virus, varicella-zoster, Crohn's disease, and Behçet's disease. Genital bleeding can be caused by urethral prolapse, vaginal foreign body, or noninflicted trauma.

The medical exam should begin with a general exam of the child. Doing so enables the child to become comfortable with the exam process before the genital exam and may identify other evidence of maltreatment or health problems. For prepubertal children, the parent should be present to provide comfort and reassurance. Older children should be given the option of having a parent present. The American Academy of Pediatrics (AAP) recommends that whenever "private" parts are examined (i.e., genitals, breast, anus), a chaperone should be present. In prepubertal children, this can be a parent. For adolescents, the chaperone should be a clinical staff member, unless the teen objects. If so, the PCP may have a parent be present if all three

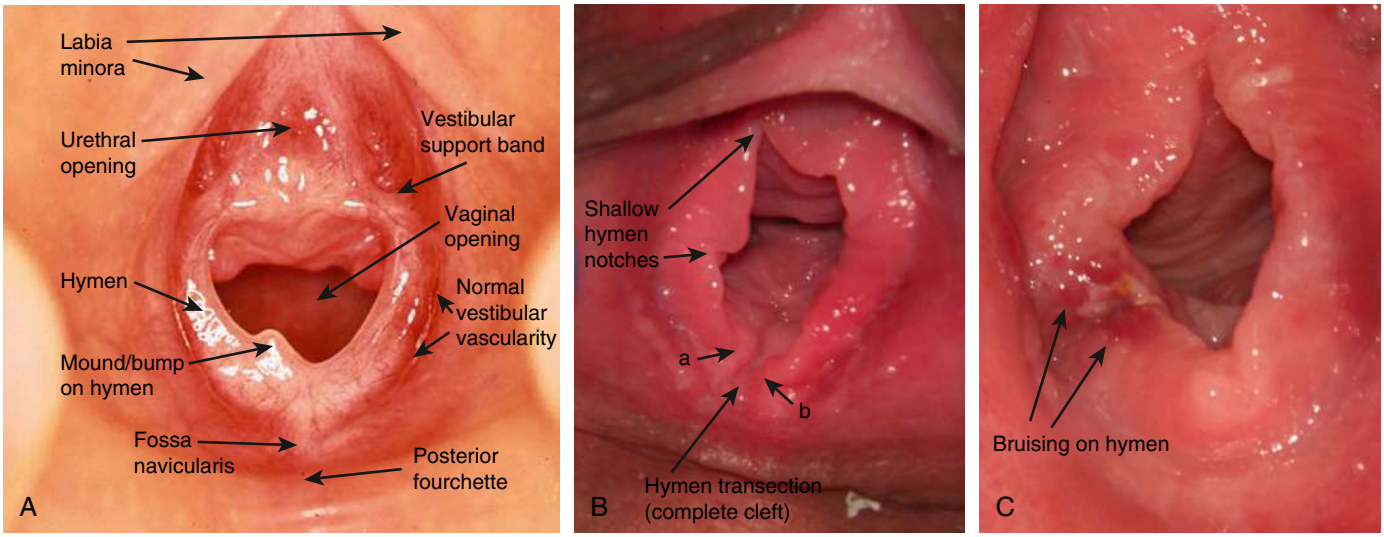

Fig. 17.10 **A,** Photograph taken with a camera attached to colposcope at 10× magnification. Note the increased vascularity and redness in the vestibule adjacent to the hymen on the right and left. This is a normal finding and not to be mistaken for signs of trauma. **B,** Photograph taken with a camera attached to colposcope at 10×magnification shows the appearance of the hymen in an adolescent. Shallow notches in the hymen are evident at the 9 and 11 o'clock positions, as well as hymen transection at approximately 7 o'clock. There is no hymen tissue between *arrow a and arrow b,* confirming that the defect extends all the way through the hymen tissue. **C,** Photograph taken with a camera attached to a colposcope shows bruising of the hymen at the 7 to 8 o'clock position and the suggestion of a possible hymen laceration. Examination of additional positions and other examination techniques would be required to determine if a hymen laceration is also present at this location. (*From Adams JA, Kellog ND, Moles R. Medical care for children who may have been sexually abused: an update for 2016. J Pediatr Adolesc Gynecol. 2015;17(4):255–263. Figs. 1, 2, and 4.)*

are amenable. The PCP may decline to do an exam if the teen refuses a chaperone.

The female genital exam is done with the child in the frog-leg supine position or the adolescent in the lithotomy position. Labial separation and labial traction, with gentle tugging apart and down of the labia majora, provide a view of the hymen. Any suspected abnormalities should be confirmed by also examining the child in the prone knee-chest position. Supine knee-chest is the best way to examine the anus. Internal vaginal and anal exams are rarely needed. If there is significant bleeding or a persistent discharge, a referral to an expert in child abuse is recommended.

Referral to a child abuse specialist: Referral to a child abuse specialist will help ensure that findings indicative or suggestive of abuse are appropriately identified and documented. It is considered the standard of care to use a colposcope or camera for the genital exam to magnify the genital and anal tissues for improved visualization and to take photographs or video as potential evidence and for peer review. Child abuse experts can identify mimics of sexual abuse, test for and treat STIs, and address child or parental concerns.

Testing for STIs: Testing for STIs is not indicated for most children but is warranted in certain situations (Table 17.6). *Culture* was considered the gold standard for diagnosing vaginal gonorrhea (Chapter 238) and chlamydia (Chapter 272) infections in children. Nucleic acid amplification testing (NAAT) for gonorrhea and chlamydia by either vaginal swab or urine in prepubertal girls is as, or more, sensitive than culture. Guidelines from the Centers for Disease Control and Prevention (CDC) allow for such NAAT testing as an alternative to culture. Because obtaining vaginal swabs can be uncomfortable, particularly for prepubertal girls, urine testing is preferable, using a Food and Drug Administration (FDA)–approved assay. Although the FDA has not approved NAATs for the diagnosis of gonorrhea or chlamydia infections of the throat or anus, they may be used if the laboratory has performed internal validation with reference standards. Although little data on the use of urine NAAT testing in prepubertal boys are available, the CDC has indicated that there is no reason to suspect that test performance in children and youth would be different from adults. Thus urine testing of them too appears adequate.

Table 17.6 Indications for STI Screening in Children with Suspected Sexual Abuse

1. The child has experienced penetration or has evidence of recent or healed penetrative injury to the genitals, anus, or oropharynx.
2. The child has been abused by a stranger.
3. The child has been abused by an assailant known to be infected with an STI or at high risk for STIs (e.g., injecting drug user, men who have sex with men, persons with multiple sexual partners, or person with a history of STIs).
4. The child has a sibling, other relative, or another person in the household with an STI.
5. The child lives in an area with a high rate of STIs in the community.
6. The child has signs or symptoms of STIs (e.g., vaginal discharge or pain, genital itching or odor, urinary symptoms, or genital lesions or ulcers).
7. The child or parent requests STI testing.
8. The child is unable to verbalize details of the assault.

STI, Sexually transmitted infection.
From Workowski KA, Bachmann LH, Chan PA, et al. Sexually transmitted infections treatment guidelines, 2021. *MMWR Recomm Rep.* 2021;70(4):1–184.

For all NAAT testing in females and males, the child should *not* receive presumptive treatment at the time of testing. Instead, a positive NAAT test should be confirmed by repeating the test on the original sample or on a new sample. Whereas the CDC previously recommended confirmatory testing with a different FDA-approved assay, the 2021 Sexually Transmitted Infection Treatment Guidelines no longer require this. Gonorrhea and chlamydia in prepubertal children rarely cause ascending infection; thus waiting for a definitive diagnosis before treatment holds little risk for pelvic inflammatory disease.

Testing for *Trichomonas vaginalis* is by culture, NAAT, or wet mount. Wet mount requires the presence of vaginal secretions, viewing must be immediate for optimal results, and sensitivity is only

Table 17.7 Implications of Commonly Encountered Sexually Transmitted or Sexually Associated Infections for Diagnosis and Reporting of Sexual Abuse Among Infants and Prepubertal Children

INFECTION	EVIDENCE FOR SEXUAL ABUSE	SUGGESTED ACTION
Gonorrhea*	Diagnostic†	Report†
Syphilis*	Diagnostic	Report†
HIV§	Diagnostic	Report†
*Chlamydia trachomatis**	Diagnostic†	Report†
*Trichomonas vaginalis**	Diagnostic	Report†
Anogenital herpes	Suspicious	Consider report†,¶
Condylomata acuminata (anogenital warts)*	Suspicious	Consider report†,¶,**
Anogenital molluscum contagiosum	Inconclusive	Medical follow-up
Bacterial vaginosis	Inconclusive	Medical follow-up

*If unlikely to be perinatally acquired and vertical transmission, which is rare, is excluded.
†Reports should be made to the local or state agency mandated to receive reports of suspected child abuse or neglect
§If unlikely to have been acquired perinatally or through transfusion.
¶Unless a clear history of autoinoculation exists.
**Report if evidence exists to suspect abuse, including history, physical examination, or other identified infections. Lesions appearing for the first time in a child aged >5 yr are more likely to have been caused by sexual transmission.
From Workowski KA, Bachmann LH, Chan PA, et al. Sexually transmitted infections treatment guidelines, 2021. *MMWR Recomm Rep.* 2021;70(4):1–184. Adapted from Kellogg N, American Academy of Pediatrics Committee on Child Abuse and Neglect. The evaluation of sexual abuse in children. *Pediatrics.* 2005;116:506–512; Adams JA, Farst KJ, Kellogg ND. Interpretation of medical findings in suspected child abuse: An update for 2018. *J Pediatr Adolesc Gynecol.* 2018;31:225–231.

44–68%; therefore false-negative tests are common. NAAT tests for *Trichomonas* should only be performed using FDA-approved products. Positive tests should be confirmed using the same sample or a repeat collection. Point-of-care tests for *Trichomonas*, done at the PCP's office, have not been validated for prepubertal children and should not be used.

Obtaining a blood sample for HIV, syphilis, and hepatitis B testing should be considered, particularly if there has been vaginal or anal penetration with pain, bleeding, or ejaculation. To limit painful procedures, some experts begin with genital, anal, and/or throat testing and do the blood testing if the earlier testing is positive. Because HIV testing identifies antibodies to the virus, it may take several months for seroconversion—repeat testing at 6 weeks and 3 months after the last suspected exposure is indicated. Repeat testing for syphilis and hepatitis B is also recommended at the same intervals.

INTERPRETATION OF FINDINGS

History: A clear disclosure of abuse by a child or adolescent, particularly with details that can be corroborated, is strong evidence that abuse has occurred. A strong denial could indicate that abuse did not occur, but could also be the result of fear, threats from the perpetrator, or pressure from family members to remain silent. Limited language skills or a long length of time since the abuse occurred may limit the specificity of the disclosure. Alternatively, a vague disclosure may lead a parent to assume abuse when none has occurred. Infrequently, a child may be coached by a parent to describe abuse, sometimes in the context of a custody dispute. More commonly, an abusive parent will allege coaching to protect themself and enable ongoing access to the child.

Findings indicative of trauma: Abrasions, lacerations, and bruising of the labia, vulva, penis, scrotum, perianal tissues, or perineum indicate recent trauma. Hymenal bruising and lacerations and deep perianal lacerations (vs superficial fissures) indicate penetrating trauma. Anogenital scars indicate older trauma. Hymnal scars often appear as changes in the usual anatomy and pallor. It is noteworthy that such findings that are exactly midline are likely normal embryonic remnants. A complete transection of the hymen all the way to the base below 3 and 9 o'clock in the supine position (i.e., absence or gap of hymenal tissue posteriorly) is considered diagnostic for penetrating trauma (see Fig. 17.10). For all these findings, the cause of injury must be elucidated through the child and parent history, as trauma may also be the result of a noninflicted injury or consensual sexual activity. If there is any concern that the finding may be the result of sexual abuse, CPS should be notified, and a medical evaluation should be performed by a medical specialist with expertise in child sexual abuse.

STIs: A number of STIs raise serious concern for abuse (Table 17.7). In a prepubertal child, **gonorrhea**, **trichomonas**, or **syphilis** beyond the neonatal period indicates that the child had contact with infected genital secretions, almost always as a result of sexual abuse. There is some evidence to indicate that **chlamydia** in children up to 3 years of age may be perinatally acquired. Chlamydia in children older than 3 years is diagnostic of contact with infected genital secretions almost always because of abuse. **HIV** is diagnostic for sexual abuse if other means of transmission have been excluded. Because of the potential for human papillomavirus (HPV) transmission, either perinatally or through nonsexual contact, the presence of **genital warts** has a low specificity for sexual abuse. Nevertheless, the possibility of abuse should be briefly probed with the family, especially in children whose warts first appear beyond 5 years of age. **Type 1 or 2 herpes simplex virus (HSV)** in the anogenital area is concerning for sexual abuse, but not diagnostic given other possible routes of transmission. PCPs should consider referring patients with HPV and HSV to CPS.

Integration of Information

Because most sexually abused children have normal exams, it is often not possible to make a diagnosis of sexual abuse by the exam alone. Ideally, the determination of abuse should be made as part of a multidisciplinary team process, where information from interviews, medical evaluation, forensic kit, and laboratory test results are integrated. Determinations by CPS as to whether abuse occurred may not align directly with a decision to prosecute alleged offenders because criminal cases require a higher level of proof (beyond a reasonable doubt) than do CPS cases, which rely on the preponderance of evidence (i.e., more likely than not).

Recommendations for Children and Families

At the conclusion of the medical evaluation, the PCP should let the child and parent know that the child is physically healthy but should also explain to them why a normal exam does not rule out abuse. It is often helpful to reinforce that in most cases, what is most important in determining whether sexual abuse occurred is what the child has said. When there are findings indicative of abuse, these should also be clearly explained. Of note, injuries to the anogenital area typically heal without complications, and most STIs respond well to treatment. Thus comforting and reassuring children and families is generally appropriate, even when injuries and/or infection occurs. PCPs should tell children that the abuse was not their fault and encourage parents to be supportive of their child. Although most children will not need medical follow-up, a visit with their PCP can be helpful to monitor psychosocial progress and to support the child and family. Some will need repeat HIV, syphilis, and hepatitis B testing. Hepatitis B and HPV vaccination (for children ≥9 years) should be given if the child has not been adequately vaccinated. Most children and their parents benefit from therapy or counseling. A mental health evaluation for other children in the home should be considered; the stress of coping with abuse and its ramifications can be difficult for the entire family. Parents are often very stressed by the sexual abuse of their child, even when it is uncertain what happened. This is compounded by the legal processes and implications. If emotional or behavior problems arise later, the PCP should try to refer the child to a mental health professional with experience in addressing trauma.

SEXUAL ABUSE PREVENTION

PCPs can play a role in the prevention of sexual abuse by educating parents and children about sexual safety at well-child visits. During the genital exam the PCP can inform the child that only the doctor and select adult caregivers should be permitted to see their "private parts" and that a trusted adult should be told if anyone else attempts to do so. Parents and children should be encouraged to use correct terms (vagina, vulva, penis, breasts) to demystify the genitals. The pediatrician can teach parents, children, and youth how to minimize the opportunity for perpetrators to access children, for example, by limiting one-adult/one-child situations outside the home (e.g., in daycare or school) and being sensitive to another adult's unusual interest in young children. In addition, PCPs can model for parents talking with children about what to do if confronted with a potentially abusive situation. Some examples include telling children to say "no," to leave, and to tell a parent and/or another trusted adult. Conversations with children of all ages can include a discussion of consent before touching another person. Conversations with teens can include information about statutory rape and electronic dissemination of sexual photos, along with their risks. Finally, PCPs can encourage open communication between parents and children; children need to hear that their parent is there to protect them and will not be angry with them if they hear something bad. Instead, they need to know.

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17.2 Factitious Disorder Imposed on Another: Medical Child Abuse (Munchausen Syndrome by Proxy)

Howard Dubowitz and Wendy G. Lane

Munchausen syndrome describes situations in which adults falsify their own symptoms to obtain healthcare. In *Munchausen syndrome by proxy,* a parent, typically a mother, simulates or causes signs and/or symptoms in her child, resulting in unnecessary healthcare. Several terms describing this phenomenon focus on the abuse or neglect experienced by a child, including *pediatric condition falsification, caregiver-fabricated illness in a child,* and **medical child abuse (MCA)**. **Factitious disorder imposed on another (FDIA)** is a *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5) psychiatric diagnosis focused on the psychopathology in the responsible parent attempting to meet their own psychologic needs. FDIA may encompass all other titles. In some instances, such as partial suffocation, "child abuse" may be most appropriate.

Because milder forms of MCA often go undetected, its incidence is unclear, although 0.5-2 per 100,000 children is commonly cited, and it appears to be a global problem. The core dynamic is that a parent falsely presents a child for healthcare. This may be via fabricating a history, such as reporting seizures or apnea that never occurred. A parent may directly cause a child's illness, for example, by exposing a child to a toxin, medication, or infectious agent (e.g., injecting stool into an intravenous line) or smothering a child. Signs or symptoms may also be manufactured, such as when a parent withholds medication or alters laboratory samples or temperature measurements. Parents may also withhold information about normal procedures or testing done elsewhere. Preverbal children are usually involved, although older children may be convinced by parents that they have a particular problem and become dependent on the increased attention; this may lead to feigning symptoms. They may also be coached to corroborate false histories. Each of these actions may lead clinicians to suspect a health problem and thus to provide unnecessary healthcare, including intrusive tests and surgeries.

When to suspect FDIA/MCA? Consideration of MCA may be triggered when the described symptoms, their course, test results, or response to standard treatment is incompatible with any known disease or condition. The reported symptoms may be repeatedly noted by only one parent or occur only when one caregiver is alone with the child. Other risk indicators include parents who appear to need a lot of attention from physicians or who insist that the child cannot cope without them. They may refuse to leave the bedside for days.

Parents with experience in a medical field may be adept at constructing plausible presentations, although the internet provides other parents with easy access to medical information. A convincing seizure history may be offered, as a normal electroencephalogram cannot fully rule out the possibility of a seizure disorder. Even after extensive testing fails to lead to a diagnosis or treatment proves ineffective, clinicians may think they are confronting a new or rare disease and may unwittingly contribute to unnecessary testing and to a parent's belief that a real problem exists. Efforts to carefully pursue a diagnosis along with difficulty accepting uncertainty may lead clinicians to persist with testing. Clinicians generally rely on and trust parents to provide an accurate history. As with other forms of child maltreatment, accurate diagnosis of MCA requires that professionals maintain a healthy skepticism under certain circumstances; this can be difficult. Clinicians, including mental health experts, may think that they are skilled at detecting deception. Most do poorly when attempting to do so during a clinical interview.

At a systems level, limited communication among treating professionals may delay the diagnosis of MCA. The "problems" often recur repeatedly over several years. The time from first presentation until the diagnosis is made averages about 2 years. Ultimately, a diagnosis of MCA rests on clear evidence of a child repeatedly being subjected to unnecessary tests and treatment, primarily stemming from a parent's exaggeration, fabrication, or induction of symptoms or signs suggesting an illness or condition.

CLINICAL MANIFESTATIONS

Mothers are the most frequent perpetrators of MCA. They may present as devoted or even model parents who form close relationships with members of the healthcare team. Although appearing very interested in their child's condition, they may be distant emotionally. Negative test results may meet with disappointment, and they may insist on further evaluation. They may have a history

of Munchausen syndrome, though not necessarily diagnosed as such.

MCA varies in nature and severity. Males and females are equally involved. Most of the victims are infants and toddlers, but approximately 25% of cases occur in children over 6 years of age. Siblings are commonly affected. Approximately 6–9% of cases are fatal, with fatalities most often the result of poisoning or suffocation. It is important to note that children who really do have health problems can also be victims of MCA; up to 30% of patients with MCA have been found to have a medical problem. Many medical or behavioral conditions can be falsified. The following are examples of relatively common ways MCA presents:

Bleeding may be caused by adding dyes to samples, adding blood (e.g., from the mother) to the child's sample, or giving the child an anticoagulant (e.g., warfarin). Blood group testing may be needed.

Seizures are easy to fabricate and difficult to rule out. A parent may report that another physician diagnosed seizures, and the myth may be perpetuated if there is no effort to confirm the original "diagnosis." Alternatively, seizures may be induced by toxins, medications (e.g., insulin), water, or salt. Clinicians need to be familiar with the substances available to families and their risks.

Apnea may be falsified or created by partial suffocation. A history of a sibling with the same problem, perhaps dying from it, should raise concern. Parents of children hospitalized for a brief resolved unexplained event (BRUE) have been videotaped attempting to suffocate their child while in the hospital.

Gastrointestinal problems such as vomiting and diarrhea are common. Forced ingestion of medications such as ipecac may induce chronic vomiting, or laxatives may cause diarrhea. Toxicology testing is indicated in such circumstances.

Allergies may be fabricated. Sometimes, allergies may be diagnosed or considered, and a parent persists in viewing this as a problem even after it has subsequently been ruled out.

Urinary tract infections and hematuria account for about 25% of cases.

Behavior problems such as self-harm or harming others, learning disabilities, hyperactivity, or autism may be falsely described.

EVALUATION AND DIAGNOSIS

It is critical that clinicians consider the possibility of MCA in their differential diagnosis when facing the previously noted presentations. Further, it helps to focus on the actual or potential harm to a child, rather than the parent's possible motivation. Once MCA is suspected, gathering and critically reviewing **all** the child's medical records from all sources is an onerous but critical first step, best done by someone knowledgeable about MCA. Child protective services (CPS) can help gather the records, and a hospital-based child protection team might be able to review the case. Important documentation at each health contact includes date, location, reason for contact, reported signs/symptoms as stated by the caregiver, objective observations documented by the physician, conclusions/diagnosis made, treatment provided, effectiveness of treatment, and other comments or observations. It is important to confer with other treating physicians about what specifically was conveyed to the family; they may have been reluctant to document concerns in the child's record. A parent may report that a certain test was done at the insistence of a physician, when they, in fact, had demanded it. It is also sometimes necessary to confirm the exact basis for a given diagnosis, rather than simply accepting a parent's account (e.g., seizure).

Depending on the nature of the presenting problem, hospitalization may be needed. Verbal children should be interviewed alone, and the family history should probe for unusual and frequent illnesses. Close observation of a child can be valuable. There may be a history of poor appetite and vomiting, yet the child is observed to eat well without problems. Symptoms may only be described when the parent is present and otherwise noted to be absent. In some instances, such as BRUEs, covert video surveillance accompanied by monitoring (to rapidly intervene if a parent attempts to suffocate a child) can be valuable. In addition to helping clarify the diagnosis, video surveillance can identify a true medical problem. It is prudent to consult with risk management and hospital legal staff before initiating surveillance. Specimens should be carefully collected, with no opportunity for tampering with them. Similarly, temperature measurements should be closely observed.

Coordination among treating professionals is essential, especially as some may side with the parent and resent even the possibility of MCA being raised. Ideally, parents should not be informed of the evaluation for MCA until the diagnosis is made. Doing so could influence their behavior and jeopardize establishing the diagnosis. In summarizing the review of health records and gathering additional information, careful and chronologic documentation is important. This includes who witnessed symptoms, direct information from other clinicians who made diagnoses, what guidance was given to the family, whether a parent insisted on testing or treatment, and suspected tampering with equipment or records as well as other concerning behavior. It may be necessary to block parents at least temporarily from accessing part of the electronic health record.

The diagnosis of MCA hinges on a child receiving unnecessary healthcare that is actually or potentially harmful and that is instigated by a parent or caregiver. Three questions to be answered in considering MCA include:

1. Are the history, signs, and symptoms credible?
2. Is the child receiving unnecessary and harmful or potentially harmful medical care?
3. If so, who is instigating the evaluations or treatments?

Comprehensive practice guidelines regarding MCA are available from the American Academy of Pediatrics (AAP) and the American Professional Society on the Abuse of Children (APSAC). In addition, consultation with a board-certified child abuse pediatrician is strongly recommended.

Related circumstances: In assessing possible MCA, several other circumstances should be considered in addition to a true health problem. Some parents may be extremely anxious and genuinely concerned about a possible problem. There may be many reasons underpinning the vulnerable child syndrome, such as the death of neighbor's child or something read on the internet. Alternatively, parents may believe something told to them by a trusted clinician despite subsequent evidence to the contrary and efforts to correct the earlier misdiagnosis (e.g., persistent belief that the child has multiple food allergies). Secondary gain, such as qualifying for a disability benefit, may be the impetus for malingering. A child's anxiety, especially in the context of complex medical conditions, may lead to psychosomatic symptoms and consideration of MCA. In addition, parents of such children may be extremely stressed, and this may contribute to an approach that is overly medicalized (e.g., reluctance to wean a child off medication). There is also a need to discern commonly used hyperbole (e.g., exaggerating the height of a fever) to evoke concern and perhaps justify a clinic visit. Whatever the possible underlying dynamics, children who receive unnecessary healthcare as a result of parental actions can be diagnosed with MCA.

TREATMENT

MCA is a form of child abuse or neglect and needs to be referred to CPS even when one is less than certain of the diagnosis; law enforcement may also need to be involved. CPS staff often lack knowledge of and experience with MCA and may need to be educated regarding this condition. Once the diagnosis of MCA is

established, the medical team and CPS should determine the treatment and safety plan, which may require out-of-home placement and should include mental healthcare for the offending parent; psychiatric decompensation and maternal suicide have been reported. Further medical care should be carefully coordinated through one primary care professional. CPS should be encouraged to meet with the family only after the medical team has informed the offending parent of the diagnosis, together with the other parent or another supportive adult if possible. Direct CPS involvement with the family during the assessment may jeopardize clarifying the diagnosis. If the plan is to place the child out-of-home, it is optimal that CPS plan the necessary steps in advance. Parents often respond with resistance, denial, and threats. It may be prudent to have hospital security in the vicinity in case of physical aggression or an attempt to remove the child from the hospital against medical advice. CPS should assess the safety of other children in the home. All family members may be affected by an MCA diagnosis; mental healthcare is recommended specifically for the parent involved with FDIA.

Assessing and addressing MCA can be time intensive and challenging. Clinicians may face the dilemma of when to accept that all plausible diagnoses have been reasonably ruled out, the circumstances fit MCA, and when testing and treatment should cease. The likelihood of MCA must be balanced with concerns about possibly missing an important diagnosis. Consultation with a child abuse pediatrician is recommended for making the diagnosis and for helping plan ongoing healthcare if the child remains in or returns to the home. Good communication among treating clinicians is needed to adequately monitor the situation; long-term monitoring may be needed.

OUTCOMES

There may be lasting physical harms associated with unnecessary and sometimes invasive evaluations and interventions, including scarring, surgical complications, brain damage, and death. There are also potentially serious and lasting social and psychologic sequelae as a result of missing school and extracurricular activities and viewing themselves as disabled. Victims of MCA may be overly compliant or aggressive and may develop poor self-esteem, posttraumatic stress disorder, and eating problems. Indirectly, other family members and friends, professionals, and even community members may be affected. Recidivism has been reported in 17–50% of cases. Successful treatment of the abusive parent appears rare and hinges on acknowledging their role and being willing and able to change their behavior.

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Chapter 18

Strategies for Health Behavior Change

Cori M. Green

To improve the health of children, pediatricians often ask patients and caregivers to make behavioral changes. These may be lifestyle changes to manage a chronic condition (e.g., obesity, asthma), adherence with the recommended timing and frequency of medications, or recommendations to seek assistance from other health providers (e.g., dieticians; mental health providers; physical, occupational, or speech therapists). However, change is difficult and can cause distress, and families often express reluctance or ambivalence to change because of perceived barriers. When families do not believe change is needed or possible, pediatricians may become discouraged or uncomfortable in providing care. This can make it difficult for clinicians to form an alliance with families, which is central to finding a solution to most problems identified in the medical setting.

Many healthcare problems may require complex, multifaceted interventions, but the first step is always to engage the family in identifying the healthcare problem driving the need for behavior change. Once a problem is identified and agreed on, clinicians and families need to set an achievable goal and identify specific behaviors that can help families reach their goal. It is important to be specific and precise about the actual behavior and not simply identify the *category* of the behavior. When counseling a patient on weight loss for obesity, for example, one might discuss three possible approaches: making dietary changes, increasing exercise, and decreasing screen time. The choice of which behavior to focus on should come from the patient but needs to be specific. It is not enough for the patient to state he or she will exercise more. Instead, the clinician should help the patient identify a more specific goal, such as playing basketball with friends 3 times a week at the park near home. This takes into account the action, context, setting, and time of the new behavioral goal. Specific examples of problems that would necessitate a behavior change to improve outcomes are used throughout the chapter.

UNIFIED THEORY OF BEHAVIOR CHANGE

There are several theories of health-related behavior change. Each highlights a different concept, but frameworks that unite these theories suggest that the factor most predictive of whether one will perform a behavior is the *intention* to do so. The **unified theory of behavior change** examines behavior along two dimensions: influences on intent and moderators of the intention-behavior relationship (Fig. 18.1). Five main factors that influence one's decision to perform a behavior are expectancies, social norms/normative influences, self-concept/self-image, emotions, and self-efficacy. Table 18.1 provides specific examples on how to explore influences of intent when guiding families in decision-making, such as deciding to start a stimulant medication for a child diagnosed with attention-deficit/hyperactivity disorder (ADHD). It is not necessary to ask about each influence, but these principles are particularly useful when guiding patients who may be resistant to change.

Once a decision to make a change is made, four factors determine whether an intention leads to carrying out the behavior: knowledge and skills, environmental facilitators and constraints, salience of the behavior, and habits. The pediatrician can help ensure intent leads to behavior change by addressing these factors during the visit. In the ADHD example, the clinician can help the family build their knowledge by providing handouts on stimulants, nutritional pamphlets on how to minimize the appetite-suppressant effects of the medication on weight, and information on how the family can explain to others the need for medication. Asking about morning routines will help identify potential barriers in remembering to take the medication. Lastly, clinicians can help families think about cues for remembering to give the medication in the morning, because their morning routines, or habits, will have to be adjusted to adhere to this medication.

By using these principles of behavior change, clinicians can guide their patients toward change during an encounter by ensuring they leave with (1) a strong positive intention to perform the behavior; (2) the perception that they have the skills to accomplish it; (3) a belief that the behavior is socially acceptable and consistent with their self-image; (4) a positive feeling about the behavior; (5) specific strategies in overcoming potential barriers in performing the behavior; and (6) a set of identified cues and enablers to help build new habits.

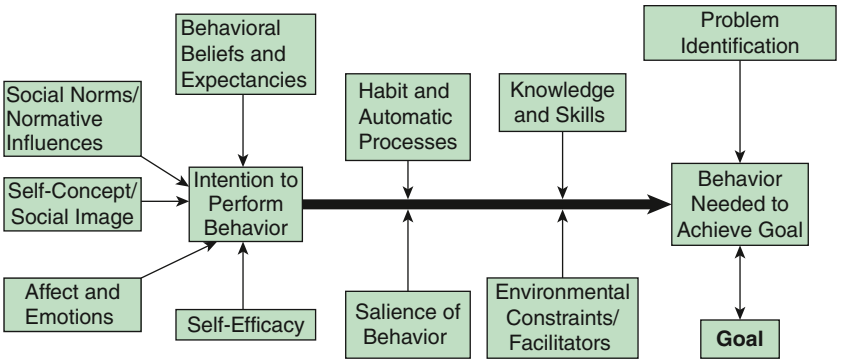

Fig. 18.1 The five constructs that influence one's intent to perform a behavior and the four influences that determine whether an intent will lead to performing the behavior. Problem identification (*box* at upper right) is where the process of thinking about health behavior changes begins. A clinician can then help the patient decide which behavior can help them meet the health goal. Once this is decided, to help with behavior change, clinicians should think about intent, influences of intent, and the factors that may facilitate or impede intent from leading to action.

Table 18.1 Influences of Intent and Possible Use During a Patient Encounter (Specifically, Starting a Stimulant for ADHD)

INFLUENCE OF INTENT	STRATEGIES TO ENGAGE FAMILIES USING INFLUENCES OF INTENT	POSSIBLE FACTORS INFLUENCING THE DECISION*
Beliefs and expectancies Perceived advantages and disadvantages of performing a behavior.	Ask questions about their beliefs and experiences. "What do you know already know about stimulants?" "Have you heard about other children's experiences taking stimulants?" "What do you expect will happen if your child takes a stimulant?" Ask permission to give information addressing their prior beliefs or experiences. "Is it all right if I give you some information addressing your concerns?"	"I know that stimulants helped my nephew do better in school." "I heard stimulants stunt children's growth."
Social norms Pressures to (or not) perform a behavior because of what is standard among social groups.	Share information about the normative nature of the behavior and ways to cope if performing a behavior that is not the social norm. "I have a lot of patients who have improved in school after starting a stimulant."	"Do other parents give their children stimulants if they are diagnosed with ADHD?" "What would my mother think if she found out my child was taking a stimulant?"
Self-concept/self-image Overall sense of self and whether behavior is congruent with that and with the image they want to project to others.	Interact with family in a partnering, supportive, respectful manner. Identify strengths. Reframe any negative images they foresee may happen with the behavior. "I am sure your in-laws will be so happy when your child is doing better in school."	"Am I a good parent if I give my child medications that affect their brain?" "What will other parents at school think if I allow my child to start a stimulant? What will my in-laws think?"
Emotions Emotional reactions to performing behaviors in terms of intensity and direction (positive or negative).	Allow patients to express their feelings. Suggest ways to manage negative or avoidant feelings. "Many parents are scared to start stimulants at first. However, once their child is succeeding in school, they realize the benefits outweighed the risks. Let's talk more about your fears."	"I am so nervous about my child starting to take a stimulant." "I am so upset with how my child is doing in school and really do not know what to do next." "I am so relieved that there is a medication that may help improve my child's grades and chance of going to college."
Self-efficacy Perceived confidence they can perform the behavior.	Provide information, model the behavior, encourage success, and teach skills. Explore what obstacles they foresee and how confident they are they can overcome obstacles. Help strategize ways to overcome obstacles. "Do you feel confident you will be able to get your child to take the medication?" "Let's brainstorm how we can prevent any of the side effects." "Many of my patients have a large breakfast before taking the medication. Can I help you figure out how to fit that into your schedule?"	"Will I be able to remember to give my child this medication every day?" "Will I be able to make sure my child has a large breakfast in the morning before taking the medication?"

ADHD, Attention-deficit/hyperactivity disorder.
*Statements and questions are examples of what caregivers may be thinking.

Table 18.2 Stages of Change and Strategies for Counseling*

STAGE/DEFINITION	GOAL AND STRATEGY	SPECIFIC EXAMPLES
Precontemplation Not considering change. May be unaware that a problem exists.	Establish a therapeutic relationship. Increase awareness of need to change.	"I understand you are only here because your parents are worried and that you don't feel that smoking marijuana is a big deal." "Can I ask if smoking marijuana has created any problems for you now? I know your parents were worried about your grades." "It's up to you to decide if and when you are ready to cut back on smoking marijuana." "Is it okay if I give you some information about marijuana use?" "I know it can be hard to change a habit when you feel under pressure. It is totally up to you to decide if cutting back is right for you. Is it okay if I ask you about this during our next visit?"
Contemplation Beginning to consider making a change, but still feeling ambivalent about making a change.	Identify ambivalence. Help develop discrepancy between goals and current behaviors. Ask about pros and cons of changing problem behavior. Support patient toward making a change.	"I'm hearing that you do agree that sometimes your marijuana use does get in the way, especially with school. However, it helps relax you and it would be hard to make a change right now." "What would be one benefit of cutting back? What would be a drawback to cutting back? Do you think your smoking will cause problems in the future?" "After talking about this, if you feel you want to cut back, the next step would be to think about how to best do that. We wouldn't need to jump right into a plan. Why don't you think about what we discussed, and we can meet next week if you are ready to make a plan?"
Preparation Preparing for action. Reduced ambivalence and exploration of options for change.	Help patient set a goal and prepare a concrete plan. Offer a menu of choices. Identify supports and barriers.	"It's great that you are thinking about ways to cut back on your smoking. I understand your initial goal is to stop smoking during the week." "I can give you some other options of how to relax and reduce stress during the week." "We need to figure out how to react to your friends after school who you normally smoke with." "Do you have other friends who you can see after school instead, who would support this decision?"
Action Taking action; actively implementing plan.	Provide positive feedback. Identify unexpected barriers and create coping strategies.	"Congratulations on cutting back. Have you noticed any differences in your schoolwork? I'm so happy to hear your grades improved." "Has it been difficult to not see your friends after school? How have you reacted when they get annoyed you don't want to smoke with them?" "Let's continue to track your progress."
Maintenance Continues to change behavior and maintains healthier lifestyle.	Reinforce commitment and affirm ability to change. Create coping plans when relapse does occur. Manage triggers.	"You really are committed to going to a good college and improving your grades. I'm so happy the hard work has paid off." "I understand that it was hard to say no to smoking with your friends last week when it was someone's birthday. How did you feel after? Are there triggers that we can think about preventing in the future?"

*This table uses an example of an adolescent who is initially resistant to cutting back on smoking marijuana. His parents caught him smoking in his room and arranged for him to see the pediatrician.

Adapted from *Implementing Mental Health Priorities in Practice: Substance Use,* American Academy of Pediatrics. https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Mental-Health/Pages/substance-use.aspx.

TRANSTHEORETICAL MODEL OF HEALTH BEHAVIOR CHANGE

It is difficult to counsel families to change a behavior when they may not agree there is a problem or when they are not ready to build an intention to change. The **transtheoretical model of health behavior change** places an individual's motivation and readiness to change on a continuum. The premise of this model is that behavior change is a process, and as someone attempts to change, they move through five stages (although not always in a linear fashion): *precontemplation* (no current intention of making a change), *contemplation* (considering change), *preparation* (creating an intention, planning, and committing to change), *action* (has changed behavior for a short time), and *maintenance* (sustaining long-term change). Assessing a patient's stage of change and then targeting counseling toward that stage can help build a *therapeutic alliance,* in contrast to counseling a patient to do something she or he is not ready for, which can disrupt the therapeutic alliance and lead to resistance. Table 18.2 further describes stages of change and gives examples for counseling that target the adolescent's stage of change in reducing marijuana smoking.

COMMON FACTORS APPROACH

Conversations around behavior change are most effective when they take place in a context of a trusting, mutually respectful relationship. The traditional medical model assumes that patients and their families come with questions and needs and that the pediatrician's job is to offer specific advice and advocate for its acceptance. This approach fails when families are reluctant, ambivalent, demoralized, or unfamiliar with the healthcare system or the treatment choices offered. A context more supportive of behavior change can be developed when clinicians use communication strategies that facilitate collaboration and building a therapeutic alliance.

The **common factors approach** is an evidence-based communication strategy that is effective in facilitating behavior change. The skills central to a common factors approach are consistent across multiple forms of psychotherapy and therefore can be considered transdiagnostic. Common factors and processes can be viewed as generic aspects of treatment that can be used across a wide range of symptoms to build a therapeutic alliance between the physician and patient. This alliance predicts outcomes of counseling more than the specific modality of treatment. The common factors approach has been implemented and

Table 18.3 Hope, Empathy, Language, Loyalty, Permission, Partnership, Plan (HEL^{2}P^3)*

SKILL	EXAMPLES
Hope for improvement: Develop strengths.	"I have seen other children like you with similar feelings of sadness, and they have gotten better."
Empathy: Listen attentively.	"It must be hard for you that you no longer get pleasure in playing soccer."
Language: Use family's language. Check understanding.	"Let me make sure I understand what you are saying. You no longer feel like doing things that made you happy in the past?"
Loyalty: Express support and commitment.	"You are free to talk to me about anything while we work through this."
Permission: Ask permission to explore sensitive subjects. Offer advice.	"I would like to ask more questions that you may find more sensitive, is that okay?" "Is it okay with you if I give you my opinion on what may be the problem here?"
Partnership: Identify and overcome barriers.	"Can we discuss together possible solutions to overcoming your discomfort in getting therapy?"
Plan: Establish a plan, or at least a first step the family can take.	"If we work together, maybe we can think through solutions for the problems you identified."

*This table illustrates the **interpersonal skills** highlighted in the common factors approach. In this example the clinician is responding to an adolescent struggling with depression and resistant to seeking help.

Adapted with data from Foy JM, Kelleher KJ, Laraque D. American Academy of Pediatrics Task Force on Mental Health. Enhancing pediatric mental health care: Strategies for preparing a primary care practice. *Pediatrics.* 2010;125 Suppl 3:S87–S108.

studied in pediatric primary care for children with mental health problems. Children who were treated by pediatricians trained in the common factors approach had improved functioning compared to those who saw pediatricians without this training.

A common factors approach distinguishes between the impact of the patient-provider alliance and the pediatrician's use of skills that influence patient behavior change across a broad range of conditions. Interpersonal skills that help build alliances with patients include showing empathy, warmth, and positive regard. Skills that influence behavior change include a clinician's ability to provide optimism, facilitate treatment engagement, and maintain the focus on achievable goals. This can be done by clearly explaining the condition and treatment approaches while keeping the discussion focused on immediate and practical concerns.

Interpersonal Skills: HEL^{2}P^3

The interpersonal skills that facilitate an effective bond between the patient and clinician can be remembered by the HEL^{2}P^3 mnemonic (Table 18.3). These skills include providing **hope**, **empathy**, and **loyalty**; using the patient's **language**; **partnering** with the family; asking **permission** to raise more sensitive questions or to give advice; and creating a **plan** that is initiated by the family. These interpersonal skills should help operationalize the common factors approach by increasing a patient's optimism, feelings of well-being, and willingness to work toward improved health, while also targeting feelings of anger, ambivalence, and hopelessness.

Structuring a patient encounter using common factors to facilitate behavior change uses these steps: eliciting concerns while setting an agenda and agreeing on the nature of the problem; establishing a plan; and responding to anger and demoralization and emphasizing hope.

Elicit Concerns: Set the Agenda and Agree on the Problem

The first step of the visit is to elicit both the child's and the parent's concerns and agree on the focus for the visit. This can be accomplished by using open-ended questions and asking "anything else?" until nothing else is disclosed. It is important to show you have time and are interested in their concerns by making eye contact, listening attentively, minimizing distractions, and responding with empathy and interest. Engage both the child and the parent by taking turns eliciting their concerns. It is helpful to summarize their story to reassure them you have heard and understand what they are saying. Keep the session organized, and manage rambling by gently interrupting, paraphrasing, asking for additional concerns, and refocusing the conversation. These same principles apply for telehealth visits. Make sure you are looking into the camera and use exaggerated responses. It is particularly helpful to frequently summarize the child's and parents' concerns, voice observations, and use reflective statements during telehealth visits so the family does see that you are listening to them.

By the end of this step in the visit, all parties should feel reassured that their problems were heard and accurately described. The next step is to agree on the problem to be addressed during that visit. If the parent and child do not agree on the issue, try to find a common thread that will address the concerns of both.

Establish a Plan

Once a problem is agreed on, the clinician can partner with families to develop acceptable and achievable plans for treatment or further evaluation. Families should take the lead in developing goals and the strategies to attain them, and information should be given in response to patients' expressed needs. Pediatricians can involve families by offering choices and asking for feedback. Advice should be given only after asking a family's permission to do so. If the family asks for advice, the clinician should respond by considering principles of behavior change, as described earlier. Advice should be tailored toward the family's willingness to act, concerns for barriers, and attitudes and should be as specific and practical as possible. Once an initial plan is established, it is important to partner in monitoring responses and to provide continued support.

Respond to Anger and Demoralization and Emphasize Hope

The common factors approach is particularly helpful in engaging families in situations where anger and demoralization could prevent patients from being able to use the clinician's advice. Focusing the conversation on goals for the future and how to achieve them is more productive than discussing how problems began. This "solution-focused therapy" approach grew out of the need for clinicians to help people in a brief encounter. Hopelessness can be relieved by pediatricians helping patients to identify and build on strengths and past success, reframing events and feelings, and breaking down overwhelming goals into small, concrete steps that are more readily accomplished. In general, pediatricians can use the **elicit-provide-elicit model**. After eliciting a concern or hearing about patients' goals, ask if they want to hear your thoughts about the situation. Provide guidance in a neutral way, and then ask the family what they think about what you just stated.

Table 18.4 provides an example of how to use common factors in practice using a scenario of an adolescent female who has been teased for using albuterol before physical education class for her exercise-induced asthma. The clinician in the scenario attempts to address both the patient's and her mother's concerns.

Table 18.4 Common Factors Approach in Practice*

GOAL	SPECIFIC SKILLS	EXAMPLES
Elicit child's and parents' concerns.	Use open-ended questions and ask, "What else?" until nothing else is listed, while engaging both parties and demonstrating empathy.	"Hi, Jacqueline and Mrs. Smith. How have things been since last time? What are your biggest concerns for today?" "What else do you think we should put on the agenda for today?" "I am sorry to hear that you have had more asthma symptoms around gym time, Jacqueline. I'd like to ask you a few more questions to get a better understanding of what has changed, if that's okay with you." "I understand this is upsetting you, Mrs. Smith, and that you worry that Jacqueline is not going to the nurse before gym to use her inhaler pump anymore. Let's hear from Jacqueline."
	Agree on the problem.	"Can we all agree that managing the asthma symptoms around gym time is the most pressing issue for today? Should we focus on that today?"
	Manage rambling.	"What you're saying is really important, but I want to be sure we have time to talk about controlling your daughter's asthma symptoms during gym. Is it okay if we go back to that topic?"
Partner with families to find acceptable forms of treatment.	Develop acceptable plans for treatment of further diagnoses.	"I believe we can develop a plan to help deal with this. Is it okay to start talking about next steps?" "I am happy to give suggestions on how to more easily use your inhaler before gym, without the other kids noticing. But what were you thinking, Jacqueline?" "Let's brainstorm how you would respond to your classmates if they see you using your inhaler."
	Address barriers to treatment.	"Is there anything that makes you worry that this may not work?"
Increase expectations that treatment will be helpful.	Respond to hopelessness, anger, and frustration.	"I realize it wasn't your choice to come here, Jacqueline, but I'm interested in hearing how you feel about this issue." "It must be really hard for you, Jacqueline, when the kids tease you about your inhaler. Discussing this with your mom and me was very brave, and now we can help you." "It must be frustrating for the school nurse to call you in the middle of the day at work, Mrs. Smith." "I would be angry, too, if I felt my mom didn't understand how it felt when I got teased for going to the nurse's office."
	Emphasize hope.	"We've managed difficult things before. Remember when Jacqueline kept getting admitted for her asthma when she was younger? We have come a long way since then, and I'm sure we can manage this as well."

*Jacqueline is an adolescent female who has had asthma since she was an infant. Despite multiple hospitalizations as an infant, her asthma had been under control except for during exercise, including physical education (PE) class. She had been going to the nurse's office to take albuterol before PE class, but recently she had been teased for having to take medication before PE. She has begun to skip treatments to avoid the teasing. However, her mother has now been called a few times to pick her up from school because of her asthma symptoms. Jacqueline's caregiver is a single parent who cannot miss work and is very frustrated. She was not aware of the bullying Jacqueline has undergone.
This scenario is adapted from the American Academy of Pediatrics curricula on common factors. https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Mental-Health/Pages/Module-1-Brief-Intervention.aspx.

MOTIVATIONAL INTERVIEWING

Motivational interviewing (MI) is a goal-oriented, supportive counseling style that complements the HEL^{2}P^3 framework and is useful when patients or families remain ambivalent about making health-related behavior changes. MI is designed to enhance intrinsic motivation in patients by exploring their perspectives and ambivalence. It is also aligned with the transtheoretical model's continuum of change, where the clinician not only tailors counseling to a patient's stage of change but does so with the goal of moving the patient toward the next stage. It is particularly effective for those not interested in change or not ready to make a commitment. MI has been shown to be an effective intervention strategy for decreasing high-risk behaviors, improving chronic disease control, and increasing adherence to preventive health measures.

MI is a collaborative approach in which the pediatrician respects patients' perspectives and treats them as the "expert" on their values, beliefs, and goals. *Collaboration, acceptance, compassion,* and *evocation* are the foundation of MI and are referred to as the "spirit" of the approach. The clinician is a "guide," respecting patients' autonomy and their ability to make their own decision to change. The pediatrician expresses genuine concern and demonstrates that he or she understands and validates the patient's or family's struggle. Using open-ended questions, the pediatrician evokes the patient's own motivation for change.

Expressing empathy facilitates behavior change by accepting the patient's beliefs and behaviors. This contrasts with *direct persuasion,* which often leads to resistance. The pediatrician must reinforce that ambivalence is normal and use skillful reflective listening, showing the patient an understanding of the situation.

Developing a discrepancy between current behaviors (or treatment choices) and treatment goals motivates change and helps move the patient from the precontemplative stage to the contemplative stage or from the contemplative stage to preparation, as described in the transtheoretical model. Through MI the clinician can guide patients in understanding that their current behaviors may not be consistent with their stated goals and values.

Rolling with resistance, or not pushing back when suggestions are declined, is a strategy again to align with the patient. Resistance is

Table 18.5 Counseling for Obesity Using a Motivational Interviewing (MI) Approach

ACTION	SPECIFIC SKILLS	EXAMPLES
Engagement*	**O**pen-ended questions	"Now that we have finished the majority of the visit, I'd like to talk about your weight. Is that okay? How do you feel about your size?" "How do you feel about Jimmy's weight?" (directed toward caregiver)
	Affirmations	"You definitely have shown how strong you are having dealt with kids teasing you about your size." "Remember when you were having difficulties with your schoolwork? You were able to make a few changes, and now you are doing well. I am confident we can do the same with your weight."
	Reflective listening	"You are feeling like your son is the same size as everyone in your family, and you aren't concerned right now." "I hear that as a working parent, watching TV before bed really works for your family." "You're not terribly excited about having to think of ways to cook differently."
	Summary statements	"So far, we have discussed how challenging it would be to lose weight and make changes for the whole family, but you are willing to consider some simple changes."
Focusing	Set the agenda.	"We could talk about increasing the amount of exercise Jimmy has every week, reducing screen time, or making a dietary change. What do you think would work best?" "Great, so we will talk about soda. What do you like about it? How many times a week do you drink it?"
Evocation	Reinforce any change talk. Change ruler.	"Those are great reasons for thinking about cutting back on soda." "On a scale of 1 to 10, how confident are you (or how important is it) that you can cut back on soda?" "A 5. Why didn't you answer a 3?" "What would it take to bring it to a 7?"
Planning	Focus on how to make the change, not "why" anymore. Be concrete.	"Maybe completely eliminating soda is too difficult right now. Do you want to think of a couple of times during the week where you can reward yourself with a soda?" "What will you drink after school instead of soda?"

*OARS is used to engage the patient and build rapport.
Adapted from *Changing the Conversation About Childhood Obesity,* American Academy of Pediatrics, Institute for Healthy Childhood Weight. https://www.aap.org/en-us/about-the-aap/aap-press-room/pages/Changing-the-conversation-about-Childhood-Obesity.aspx.

usually a sign that a different approach is needed. As necessary, the clinician can ask permission to give new perspectives.

Self-efficacy, or a patient's belief in her or his ability to perform the behavior, is a key element for change and a powerful motivator. Clinicians can express confidence in the patient's ability to achieve change and support the patient's self-efficacy.

The process by which MI is used in a patient encounter involves the following four parts:

1. *Engagement* is the rapport-building part of the encounter. In addition to using the skills presented in the HEL^{2}P^3 framework, the MI approach highlights the use of open-ended questions, affirmations, reflective listening, and summaries (**OARS**). **Open-ended questions** should be inviting and probing, enabling the patient to think through and come to a better understanding of the problem and elicit their internal motivation. **Affirmations** provide positive feedback, express appreciation about a patient's strengths, and can reinforce autonomy and self-efficacy. **Reflective listening** demonstrates that the clinician understands the patient's thoughts and feelings without judgement or interruption. It should be done frequently and can encourage the patient to be more open. **Summarizing** the conversation in a succinct way reinforces that you are listening, pulls together all information, and allows the patient to hear his or her own motivations and ambivalence.
2. *Focusing* the visit is done to clarify the patient's priorities and stage of readiness and to identify the problem where there is ambivalence. If a patient remains resistant to change, ask permission to give information or share ideas and then ask for feedback on what they think about what you said. In the **elicit-ask-elicit model**, a clinician can deliver information about an unhealthy behavior or lifestyle decision in a nonpaternalistic manner.
3. *Evocation* is when the clinician assesses their patients' reasons for change and helps them to explore advantages, disadvantages, and barriers to change. It is important to reinforce the patient's **change talk.** Examples of change talk include an expression of desire ("I want to…"), ability ("I can…"), reasons ("There are good reasons to…"), or a need for change ("I need to…"). Clinicians can use "readiness rulers" by asking their patients to rate on a scale from 1 to 10 how important and confident they are in making a change. The clinician should then respond by asking why the patient did not choose a lower number and should follow up by asking what it would take to bring it to a higher number.
4. The *planning* stage is similar to that described in the discussion of a common factors approach and occurs once a patient is in the preparation stage on the continuum of change. A clinician can guide their patient through this stage by having them write down responses to statements such as, "The changes I want to make are…," "The most important reasons to make this change are…," "Some people who can support me are…," and "They can help me by…." A concrete plan should include specific actions and a way to factor in accountability and rewards. Table 18.5 uses a visit for counseling about obesity to demonstrate the process of MI.

SHARED DECISION-MAKING

Shared decision-making (SDM) has many similarities to the processes previously described in that it emphasizes moving clinicians away from a paternalistic approach in dictating treatment to one where patients and clinicians collaborate in making a medical decision, particularly when multiple evidence-based treatment options exist. The overall goal is to approach medical decisions using patient-centered strategies that are based on the best evidence available while aligning with family values. By definition, (1) SDM must involve two parties (clinician and patient/family); (2) information must be exchanged in both directions; (3) both parties must be aware of all treatment options; and (4) the clinician and patient/family must both bring their own knowledge and values equally into the decision-making

process. This approach is only possible when there is more than one management strategy and SDM does not put a patient at risk.

SDM is often facilitated by using evidence-based decision aids such as pamphlets, videos, web-based tools, or educational workshops. Condition-specific or more generic decision aids have been created and facilitate the process of SDM. Studies in adults show that such aids improve knowledge and satisfaction, reduce decisional conflict, and increase the alignment between patient preferences and treatment options. Although SDM is widely used and has been studied in adult populations, it is more complicated in pediatric settings because the caregiver (a surrogate for the patient) is also involved in decision-making. It important to involve the child or adolescent in SDM, as the more they are involved in SDM, the better their outcomes may be. Options must be explained in a developmentally appropriate way. Then both the parent and clinician need to assess how much the patient truly understands regarding their stated preference.

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