Professionals concerned about maltreatment of children have focused on child physical and sexual abuse, paying less attention to child neglect (Wolock & Horowitz, 1984). There are several reasons why neglect has not received the attention it deserves (Dubowitz, 1994). First, the typically vague definitions of neglect make it an amorphous phenomenon (Greenbaum et al., 2008). Many professionals are understandably unclear about what constitutes neglect, how to identify neglect, and what course of action is appropriate and effective. Second, the strong association between child neglect and poverty (Giovannoni & Becerra, 1979) often evokes a sense of hopelessness among professionals, deterring them from becoming involved in the complex issues underpinning neglect situations. Thirdly, neglect does not evoke the horror and outrage of abuse. However, more than half of the reports for child maltreatment made in the United States each year are for neglect, and the morbidity and mortality associated with neglect are as severe as with abuse (e.g., Dong et al., 2004; Dubowitz, 2007; Teicher et al., 2004). This chapter focuses on one major form of neglect—neglect of children’s health care. The chapter addresses the following: (1) definitional issues concerning neglected health care, (2) incidence, (3) etiology, (4) major manifestations, and (5) general principles for evaluation and (6) for intervention.

Legal aspects of neglect of children’s health care are discussed in Chapter 22.

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Defining Neglected Health

Neglect of health care occurs when children’s basic health care needs are not met. This broad definition focuses on basic needs of children rather than on parental omissions in care (Dubowitz, Black, Starr, & Zuravin, 1993; Greenbaum et al., 2008). A basic health care need is a need that when it is not met jeopardizes or harms a child’s health in a significant way (e.g., death of a child with diabetes due to lack of attention to medical recommendations)
PART II NEGLECT

(Geffken, Johnson, Silverstein, & Rosenbloom, 1992). Many situations do not, however, rise to the level of actual or potential harm (e.g., a missed follow-up appointment for an ear infection in a healthy child).

Implicit in the definition of neglect of health care is the likelihood that treatment will significantly benefit the child. If the benefit of treatment is uncertain (e.g., an experimental treatment for cancer), not receiving the treatment should not be construed as neglect.

The definition of neglect used in this chapter is based on a child’s unmet needs, irrespective of what specific factors may contribute to the neglect. From the child’s perspective, not receiving necessary care is neglect regardless of the reasons why such care is not provided. Contributing factors, however, are important for planning a response.

The broad definition of neglect of children’s health care used here, with its focus on the child, differs from most legal definitions of neglect, which focus on parental failure to obtain medical care for their child. Child protective services (CPS) generally confine its involvement to such legal definitions, with its focus on parental failure.

The broad child-focused definition of neglect has several advantages over the narrow legal approach. The broad definition encourages us to consider the full array of possible contributory factors. Although parents are primarily responsible for their children’s care, responsibility extends beyond parents to professionals, community agencies, and social policies, all of which influence children’s health. In focusing on a child’s needs rather than parental omissions, the broad definition is less blaming and more constructive.

There are several other important dimensions of neglect of children’s health care: actual versus potential harm, short-term versus long-term harm, concern with physical and psychological outcomes, and a continuum of care. The following case helps illustrate many of these dimensions:

Amy is a 6-year-old girl with severe asthma. She has been hospitalized four times in the past 2 years, twice in the intensive care unit. She was discharged from the hospital a week ago and given prescriptions for two medications. She comes to the office for follow-up and appears to be doing well. However, the prescriptions are not filled, and Amy has not received the recommended medications. Amy’s mother explains that she is waiting to get her paycheck to fill the prescription. Amy is an only child who lives with her mother. After school, Amy’s grandmother cares for her until her mother returns from work. There has been no contact with Amy’s father in the past 3 years, and he makes no financial contribution to Amy or to her mother.

Actual Versus Potential Harm

Does there need to be actual harm for there to be neglect, or is the risk of harm sufficient? Most state laws include potential harm in their definitions of child abuse and neglect. CPS agencies, however, overwhelmed by the
number of reports, often prioritize the more serious cases, and actual harm is usually viewed as more serious than potential harm. Excluding cases of potential harm is problematic, however, because the sequelae of neglect are often not immediate. In Amy’s case, even though Amy appears to be healthy, her history of severe asthma indicates her vulnerability. Without the prescribed medications, her risk for recurrent asthmatic attacks is substantial. Severe asthma can be lethal. In Amy’s case, not receiving the recommended medications constitutes neglect. The purpose of defining neglect is to ensure that children’s health care needs are met. If we are interested in preventing neglect, a focus on actual harm risks being too narrow, too late.

Short-Term Versus Long-Term Harm

As stated above, the impact of neglect may not be immediately apparent, instead manifesting in the long term. Amy may be doing well today, but persistent failures in following recommendations jeopardizes her health and safety.

Physical and Psychological Outcomes

Our concern with children’s health and well-being is a broad one. Accordingly, medical, dental, and mental health are all important aspects of health. Thus, a child is experiencing neglect if she has a history of hospitalizations due to severe dental or psychological problems and is not receiving prescribed medication or treatment. There could well be psychological problems related to Amy’s asthma being inadequately treated.

A Continuum of Care

We artificially categorize cases as “neglect” or “not neglect” when the reality is that adequacy of care for basic needs falls on a continuum from optimal to grossly inadequate. The child welfare system is most often involved when we encounter situations that cross a threshold into “grossly inadequate.” For example, few pediatricians would report Amy to CPS for neglect if the lapse in treatment occurred once or twice. More typically, neglect comes into focus when there is a pattern of repeated episodes that persist despite efforts to help and when harm results or is very likely to result.

Operationalizing the Definition of Neglect of Children’s Health Care

There are challenges to implementing the previous conceptual framework of neglect. How do we determine that a child’s health is being neglected? Determining the adequacy of basic needs being met is at the core of assessing
whether neglect exists. Epidemiological data guide us in some instances. For example, the risks associated with not wearing a bike helmet have been determined (Wesson, Spence, Hu, & Parkin, 2000), justifying a safety standard that children should wear helmets. Not doing so can be construed as neglect. In some cases, the child’s history is informative, such as Amy’s repeated hospitalizations for severe asthma, partly due to her not receiving prescribed medications. Finally, in some areas, common sense indicates that children’s needs are being neglected (e.g., homelessness, hunger, lack of health insurance, and young children left alone).

There are instances when it is difficult to determine whether care is adequate (e.g., emotional support). The quality of care can be judged, but it is difficult to specify the threshold of adequacy. In general, neglect is considered only when there are serious inadequacies.

Although intermediate inadequacies may not meet a neglect threshold, they may nevertheless call for intervention. For example, the family of a child who has repeated hospitalizations for asthma may benefit from specific recommendations regarding strategies to maintain a smoke-free environment and identify early warning signs of asthma attacks.

Neglect should be considered when a child’s condition can reasonably be attributed to a basic need not being met. For example, a child may have problems with diabetes control despite careful adherence to treatment. The disease may be inherently difficult to manage. Another issue concerns our knowledge (or lack thereof) as to what constitutes adequate care. For example, missing some doses of a course of antibiotics can still be adequate; 80% adherence to treatment for a streptococcal sore throat appears adequate to eradicate the infection (Olson, Zimmerman, & Reyes de la Rocha, 1985). Assessing neglect becomes still more complex when we recognize the variability among children and their needs. For example, one 10-year-old may be mature enough to be left alone briefly, but another may not.

How Do We Determine That a Child’s Health Is Being Neglected? ____________________

Determining whether basic needs are met is at the core of assessing whether neglect exists. This section discusses factors that are relevant to this determination.

Severity

Severity is generally rated in terms of the actual or estimated potential harm as well as the degree of harm involved. For example, Amy’s untreated asthma that results in admission to the intensive care unit would be rated as most severe, a regular hospital admission less so, a visit to the emergency department still less so, followed by mild symptoms not requiring professional
attention, and, finally, no symptoms. Regarding potential harm, some risks entail only minor consequences, but others might be life threatening. Consideration of severity includes assessing the number of times the condition has occurred and its duration.

**Likelihood of Harm**

The likelihood of the harm occurring is important to consider. Missing a follow-up appointment for a child with eczema is very different from not seeking care for an infant who has been vomiting and had diarrhea for days. Both the potential medical and psychological ramifications should be considered. Although longitudinal research may help estimate the likelihood and nature of long-term outcomes associated with specific lapses in care (e.g., prenatal drug exposure), many neglectful situations are complicated by ongoing environmental challenges such as poverty.

**Frequency/Chronicity**

Neglect is usually inferred when there is a pattern of unmet needs. A dilemma arises regarding single or rare incidents that may constitute neglect. In some instances, omissions in care are unlikely to be harmful unless they are recurrent. For example, there may be serious risks for a child with a seizure disorder who repeatedly does not get medication but not if there is only an occasional lapse. However, an infant left unattended in a bath once, briefly, could drown. Thus, this single lapse could be construed as neglect. The intervention is likely to be different if there is a pattern of neglect.

Measuring the frequency or chronicity of a problem is difficult. In some instances, medical or pharmacy records show appointments not kept or prescriptions not filled. At times, parents or children may disclose how long they have had food shortages or problems accessing health care. In sum, neglect can be defined as occurring when a child’s basic need is not met. Actual and potential harm are both of concern.

**Incidence/Prevalence**

It is difficult to estimate the extent of neglected health care. Health care providers do not identify many cases of health care neglect, and they may not report identified cases to CPS. In 2008, 71% of the 772,000 substantiated CPS reports were for neglect, <1% for medical neglect, 16% for physical abuse (PA), 9% for sexual abuse, and 7.3% for psychological maltreatment (PM). It should be noted that most states do not separately record medical neglect. In 2008, it is estimated that 39.7% of fatalities were caused by multiple forms of maltreatment. Neglect was responsible for nearly 32% of fatalities.
Most fatalities attributable to neglect were caused by lapses in supervision. One study documented 172 known deaths of children in the United States in which medical care was withheld on religious grounds; in most cases medical care would likely have saved their lives (Asser & Swan, 1998).

There is also research that focuses on societal neglect—that is, circumstances where children’s basic needs are not adequately met due largely to gaps in services and inadequate policies and programs. For example, children’s mental health needs are often not met (U.S. Department of Health and Human Services, 1999). One study of youth between ages 9 and 17 years found that only 38% to 44% of children meeting stringent criteria for a psychiatric diagnosis in the prior 6 months had had a mental health contact in the previous year (Leaf et al., 1996). Neglected dental care is widespread. For example, a study of preschoolers found that 49% of 4-year-olds had cavities, and fewer than 10% were fully treated. Another study found that 8.6% of kindergarteners needed urgent dental care (Tang et al., 1997). Neglected health care is not rare. If access to health care and health insurance is viewed as a basic need, then 8.7 million children experienced this form of neglect in 2006 (Cover the Uninsured, 2009).

**Etiology**

There is no single cause of child neglect. Belsky (1980) proposed an ecological theory of multiple and interacting factors at the individual (parent and child), familial, community, and societal levels. A toddler with a chronic, toxic blood lead level illustrates this theory. This child’s health is being neglected by a lack of protection from lead and a lack of satisfactory treatment. Contributory factors may include the parents’ unwillingness to allow treatment, the parents’ inability to move to a lead-free home, a landlord’s refusal to have the home deleded, a city’s inability to ensure an adequate lead abatement program, and society’s limited investment in low-income housing. Understanding a neglectful situation requires an appreciation of all contributory factors so we can intervene optimally. Regardless of which contributory factors are responsible, a child with a high lead level experiences neglect.

**Context—Society and Community**

Context refers to the environment in which children live, including poverty, culture, and religion, as well as the community. The context shapes the attitude, knowledge, and behavior of parents and the quality of health care children receive. Poverty has been strongly associated with neglect: Neglect was identified 44 times more often in families with annual incomes under $15,000 compared with those earning above $30,000 (Sedlak &
Broadhurst, 1996). It should be noted, however, that most children raised in poor families do not experience neglect. They do, however, experience the adverse effects of poverty, arguably a form of societal neglect (Black & Krishnakumar, 1999).

Another aspect of context concerns culture and religion. Different cultures differ in their beliefs regarding health care. For example, children from Southeast Asia may receive the folkloric remedy of *Cao Gio* for a fever (Yeatman & Dang, 1980). A hard object is vigorously rubbed over the chest and may cause bruising. It is unclear whether this practice results in any benefit or significant harm, but there is the risk of not receiving appropriate care for a serious illness (e.g., meningitis). Some cultural differences are less dramatic, such as segments of the population that have little interest in psychotherapy. Variations in beliefs pose sensitive dilemmas as health care professionals strive to avoid an ethnocentric approach (“My way is right”) and to respect cultural relativism (cultures differ and all should be accepted) (Korbin & Spilsbury, 1999). When a practice clearly harms children, and when good alternatives exist, society should ensure that children’s needs for health care are adequately met.

Some parents hold religious views that are antithetical to Western medicine, believing in alternative approaches to health. For example, sick children may receive prayer from a Christian Scientist faith healer. Many illnesses (e.g., colds) are self-limiting, and satisfactory outcomes result regardless of treatment; other illnesses, however, can lead to serious harm without effective health care.

The community and its resources influence parent-child relationships and are strongly associated with maltreatment (Garbarino & Crouter, 1978). A community with a rich array of services such as parenting groups, child care, and good public transportation enhances the ability of families to nurture and protect children. Informal support networks, safety, and recreational facilities are important in supporting healthy family functioning. Families in a high-risk environment are less able to give and share and might be mistrustful of neighborly exchanges (Garbarino & Sherman, 1980). Neglect is strongly associated with social isolation (Polansky, Ammons, & Gaudin, 1985). In one large study, mothers of neglected children perceived themselves as isolated and as living in unfriendly neighborhoods (Polansky, Gaudin, Ammons, & Davis, 1985). In summary, communities can either offer valuable support to families or add to the stresses families experience.

**Family**

Disorganization of the home is characteristic of families of neglected children. Kadushin (1988) described chaotic families of neglected children, with impulsive mothers who repeatedly showed poor planning. Deficient problem-solving skills, poor parenting skills, and inadequate knowledge of children’s needs are associated with neglect (Azar, Robinson, Hekemian, &
The absence of fathers or their limited involvement in their children’s lives may be factors in neglect (Dubowitz et al., 2001). Several studies have found more negative interactions between mothers and their young children in families of neglected children (e.g., Crittenden, 1988). Some cases of failure to thrive (FTT) are rooted in “a poor fit” between mother and child (Black, Feigelman, & Cureton, 1999). A child’s passive or lively temperament may displease a parent. In addition, family problems such as spousal violence or lack of social support may contribute to a difficult parent–child relationship (Polansky et al., 1985; Wolock & Horowitz, 1979). In contrast, a supportive family can buffer the stresses that impair parenting, illustrating the importance of considering both risk and protective factors in assessing families for possible neglect.

Stress also has been associated with child maltreatment. One study found the highest level of stress—concerning unemployment, illness, eviction, and arrest—among families of neglected children, compared with abusive and control families (Gaines, Sangrund, Green, & Power, 1978). Lapp (1983) found stress to be frequent among parents reported to CPS for neglect, particularly regarding family relationships and financial and health problems.

Parents

Many of the characteristics of mothers of neglected children may contribute to children’s health care needs not being met. Mothers’ emotional problems, intellectual deficits, and substance abuse are associated with neglect. Emotional disturbances, especially depression, are found among mothers of neglected children (e.g., Polansky, Chalmers, Williams, & Buttenwieser, 1981). Intellectual impairment including mental retardation and a lack of education is associated with neglect (Kadushin, 1988; Martin & Walters, 1982; Wolock & Horowitz, 1979). High rates of substance abuse are found among families of neglected children (Ondersma, 2002). Maternal drug use during pregnancy has become a pervasive problem (Singer, 1999). Most illicit drugs pose definite risks to the fetus and child (Accornero et al., 2007). The compromised caregiving abilities of drug-abusing parents are a major concern.

Most decisions regarding children’s health care are made by parents, including when to seek professional care. Crittenden’s (1993) model helps refine our understanding of parental difficulties by considering four steps: (1) perception of the child’s problem, (2) interpretation of the problem, (3) response, and (4) implementation. Difficulties at any of these steps may lead to unmet health care needs. The parent first needs to perceive the problem. Subtle signs such as decreased urination may go undetected. Inadequate knowledge about children and health and inappropriate expectations contribute to neglect. At times, parents may be in denial about a child’s condition. Parents of neglected children are less knowledgeable about developmental milestones (Twentyman & Plotkin, 1982) and have limited knowledge about parenting, poor skills, and low motivation to be a good parent (Herrenkohl et al., 1983).
Parents may perceive the problem but interpret it incorrectly. For example, based on the parent’s prior experience, a child’s poor growth may seem normal. A parent may believe moodiness is common in children, unaware that children can be depressed. Popular interpretations of a symptom such as an infant crying because “he’s spoiled” may lead to a problem being missed. Again, parents with limited cognitive abilities or emotional problems may have difficulty interpreting their child’s cues, determining the care needed, and understanding and implementing the treatment plan.

After recognizing and interpreting the problem, parents choose their response. Initially, they may hope the problem will resolve spontaneously or with a home remedy. For example, parents may hope a small burn will heal without professional care—a reasonable assumption. If the condition deteriorates, only then may it be clear that medical care is needed. Such delays have been viewed suspiciously, but it is important not to misjudge reasonable delays. In considering delay, the context should be considered. If care was obtained at a point when a reasonable layperson could be expected to have recognized the need for professional help then it is not a neglectful situation. An inappropriate response, including delay, may result from inadequate knowledge, parental distress, and cultural or religious beliefs. For example, a depressed youngster may not receive psychotherapy if the parents hold such treatment in disdain.

Finally, the problem may be with implementing recommendations the family has received from health care providers. A parent’s inaction may occur because the parent is distracted by other priorities (e.g., an eviction notice, obtaining drugs), depression, or difficulty accessing health care.

Other influences on parents’ behavior may be useful for professionals to consider. Confidence in the remedy or in one’s ability to implement the treatment is important (Liptak, 1996). Thus, a parent’s belief that a medicine works enhances compliance. Motivation to address a health problem is important and may be influenced by the chronicity of the problem. With chronic problems, some parents become complacent. For all families, there is a need to balance many needs and to prioritize. For example, paying an electricity bill before filling a prescription may be appropriate in some circumstances. In other circumstances, however, such as Amy’s asthma, the decision to delay implementing recommended treatment may place the child at risk, thereby constituting neglect.

Child

Children may contribute to their own neglect, directly and indirectly. A direct example is an adolescent’s denial of diabetes, refusing to adhere to the treatment plan despite excellent efforts by caring parents. Some children give no or few cues that they need help. Children’s age may influence perceptions of their vulnerability, with more concern directed to younger children. The unmet needs of adolescents may not evoke the same level of concern.

Belsky and Vondra (1989) described how children’s health status could affect their parents’ ability to provide care. For example, premature infants
may require extended care in neonatal intensive care units, which may impair bonding and the baby’s attachment to the parents. Caring for a child born with low birth weight can be challenging, and studies have found low birth weight to be a risk factor for neglect (Brayden, Altemeier, Tucker, Dietrich, & Vietze, 1992; Kotch et al., 1989).

Children with chronic health problems or disabilities have special needs that place them at added risk (Klerman, 1985). Many parents of such children are dedicated caregivers; others may be so stressed that they are unable to provide adequate care. Diamond and Jaudes (1983) found cerebral palsy to be a risk factor for neglect, but another study found no increase in maltreatment among 500 moderately to profoundly mentally retarded children (Benedict, White, Wulff, & Hall, 1990). Sullivan and Knutson (2000) found in a population-based study that disabled children were 3.4 times more likely to be identified as maltreated than nondisabled peers (9% vs. 31%). Families of children with special health care needs are often involved with multiple professionals, and increased surveillance may bias reports of neglect. A study found that children with mental health problems were at higher risk for maltreatment but not those children with developmental disabilities (Jaudes & Mackey-Bilaver, 2008). Overall, it appears that the special health care needs of children with disabilities may overwhelm some caring and competent parents, thus contributing to neglect (Klerman, 1985; Sullivan & Knutson, 2000).

The Disorder and the Treatment

The nature of the disorder may influence children’s and parents’ responses to recommendations or treatment (e.g., Liptak, 1996). For example, a disorder that is highly visible (e.g., an ugly rash) often evokes more of a response than a disorder that is not visible (e.g., lead poisoning). Children and parents who do not perceive that the disorder is serious or do not have confidence in the treatment are less likely to adhere to recommendations. Professionals can prevent neglect by ensuring that children and families are well informed about the disorder and the effectiveness of treatment.

The severity of symptoms makes a difference. Chronic health problems may be accepted without much alarm. For example, Amy’s mother may accept that her daughter is a severe asthmatic who will periodically need to be hospitalized. This may be a valuable coping strategy, but undue complacency may result. Alternatively, a chronic and severe disease may evoke great distress that contributes to denial, such as is sometimes seen in adolescents with diabetes.

Neglect is also more likely to occur if the goals of treatment are not consistent with the goals of the child or family. For example, improving pulmonary function tests (a health professional’s goal) may mean little to Amy, compared with being able to play sports (a child’s goal). Thus, communication about the goals of the child and family and the impact of the disorder and treatment on those goals should help professionals frame the reasons for the treatment in a way that resonates with the goals of the child and family.
Concerns about side effects of treatment or doubts of its effectiveness may dissuade a parent from seeking care. Obesity is an example in which a parent may recognize the problem but be reluctant to engage in treatment that they see as burdensome. In addition to questions about the treatment, families may doubt their ability to implement recommended treatments. For example, the likelihood of neglect may be increased if a parent is anxious about injecting a child who has insulin-dependent diabetes. Professionals should help ensure that parents have both the competence and confidence to follow through with treatment.

The cost of treatment may contribute to the likelihood of neglect. For example, Amy’s mother did not fill the prescriptions because she was waiting to receive her paycheck. Sensitive questioning is necessary to determine if a family is able to purchase recommended medications or to implement recommendations. When financial resources are a problem, professionals may consider less expensive options or look for strategies to minimize costs.

Poor communication may be a problem, with the treatment not being clearly conveyed or understood. Finally, simply remembering to take a medication several times in a busy day may be a challenge contributing to neglect. Working with families to help them incorporate recommended treatment into their daily routine helps families adhere to recommendations and avoid neglect.

The nature of health care includes the relationship between a professional and family (Gorski, 2000). Ideally, there is a relationship of mutual trust and respect. Families are more likely to follow recommendations if they have confidence that the recommendations are sound, will be beneficial, and are possible to implement. Without a trusting relationship, families may be discouraged from seeking help or from following recommendations. Ideally, pediatric primary care professionals focus on prevention to avoid serious health problems, including neglect. However, primary care professionals often have many issues to cover and not enough time, compromising their ability to offer comprehensive care. If the clinic or office is not perceived as friendly and supportive, families may feel discouraged from seeking care.

**Manifestations of Neglected Health Care**

This section discusses the more common forms of neglected health care.

**Nonadherence (Noncompliance)**

**With Health Care Recommendations**

The most common form of neglected health care involves a lack of adherence with health care appointments, treatment, or recommendations, resulting in actual or potential harm (e.g., Amy not getting prescribed treatment).
Nonadherence with medical recommendations is common. For example, one study found that half of adolescents were nonadherent with medical regimens (Litt & Cuskey, 1980). Another study found only 25% of parents of children with attention deficit disorder adhered to the treatment plan; fewer than 10% consulted the physician before stopping medication (Firestone & Witt, 1982). The pervasiveness of noncompliance does not minimize its importance.

Noncompliance is not restricted to patients. Researchers have studied how well physicians manage medical conditions that have clear guidelines for treatment. Studies reveal that between 48% and 72% of doctors occasionally fail to adhere to treatment guidelines (Meichenbaum, 1989).

**Failure or Delay in Seeking Health Care**

Delay in seeking medical care for a child sometimes constitutes neglect. Consider this situation:

Joe is a 10-month-old infant brought to the emergency department following 4 days of vomiting, diarrhea, decreased appetite, lethargy, and fever. On the second day, his father spoke with their pediatrician, who recommended an electrolyte solution, fever management, and follow-up if Joe’s condition should worsen. The pediatrician mentioned that he would be leaving town for the holiday weekend, but a partner would be on call. Joe had had this problem once before, and it resolved after a few days. The emergency department staff found Joe to be at least 10% dehydrated and in need of admission to the intensive care unit. The staff were concerned that medical care had not been obtained earlier, raising a question of neglect.

Parents generally decide on the appropriate care for minor problems (e.g., a scrape, a cold, sadness at the death of a pet). As conditions become more serious, the need for professional care increases, and parents are responsible for seeking such care. Neglect occurs when necessary health care is not received or when delay is so significant that a child’s health is harmed or jeopardized (e.g., Joe). The challenge for professionals is to understand what may be contributing to delay in seeking health care.

Joe’s case highlights the importance of clear communication between professionals and caregivers. Although Joe’s father contacted the pediatrician on the second day of his son’s symptoms, Joe’s prior recovery from similar symptoms, together with the holiday weekend, may have led to the decision to recommend home management without an office visit. Daily phone contact may have alerted the pediatrician to Joe’s worsening condition prior to his need for hospitalization. Thus, Joe did not receive optimal care, although the family responded reasonably. The “system” was at fault.
Religiously Motivated Medical Neglect

Medical neglect can occur when parents actively refuse medical treatment. In some cases, parents believe an alternative treatment is preferable, perhaps because the treatment recommended by doctors is prohibited by their religion. For example, Jehovah’s Witnesses, with their prohibition of blood transfusions, routinely refuse surgery when the need for transfusions is anticipated. Other religions, such as Christian Scientists, rely on faith healers and reject Western medicine.

Situations involving religious beliefs and children’s health care can be difficult. How do we balance civil liberties, parental rights, and respect for religious belief against the medical needs of children? The principle of *parens patriae* establishes the state’s authority to protect its young citizens. If a child’s parents cannot or will not provide adequate care, the state must do so. However, 30 states have religious exemptions from their child abuse statutes. Such exemptions state, for example, “A child is not to be deemed abused or neglected merely because he or she is receiving treatment by spiritual means, through prayer according to the tenets of a recognized religion” (American Academy of Pediatrics, 1988, p. 169). These exemptions are based on the arguments of religious groups that the U.S. Constitution guarantees the protection of religious practice. This interpretation of the Constitution is challenged by court rulings prohibiting parents from martyring their children based on parental beliefs (*Prince v. Massachusetts*, 1944) and from denying them essential medical care (*Jehovah’s Witnesses of Washington v. King County Hospital*, 1968). The American Academy of Pediatrics (AAP) has strongly opposed religious exemptions, arguing that the opportunity to grow and develop safe from physical harm with the protection of our society is a fundamental right of every child. . . . The basic moral principles of justice and of protection of children as vulnerable citizens require that all parents and caretakers must be treated equally by the laws and regulations that have been enacted by State and Federal governments to protect children. (American Academy of Pediatrics, 1988, pp. 169–171)

See Chapter 22 for discussion of the legal aspects of medical neglect.

Inadequate Food

Inadequate food may manifest as repeated hunger and may place a child at risk for impaired growth, including FTT. Although food insufficiency is related to poverty, more than half of food-insufficient individuals live in employed families. Hunger remains prevalent in the United States and may adversely affect children’s growth and development. Inadequate food constitutes a serious form of neglect, and professionals should screen for food insufficiency by asking families if they have adequate food for their children.
FTT can result from inadequate nutrition. The etiology of FTT is multifactorial. The traditional classification of “organic” (i.e., medical) and “nonorganic” (i.e., psychosocial) FTT has limited usefulness; more often, there is a mixed etiology. Children with medical explanations for poor growth (e.g., celiac disease) often experience discomfort while eating and develop feeding problems. A psychosocial contribution should be considered regardless of the presence of a medical condition. In addition, psychosocial conditions should be implicated based on evidence, not simply by excluding medical causes (Black, Feigelman, & Cureton, 1999). Inadequate food in a context of psychosocial problems jeopardizes children’s health and development (Mackner, Starr, & Black, 1997).

Obesity

Pediatric obesity has dramatically increased. Over 17% of American children have a body mass index (BMI) above the 95th percentile. There is a long list of complications of obesity during childhood and adulthood.

There are multiple contributors to obesity including genetic factors. Because environmental and family factors often contribute, some cases of morbid obesity may be a form of neglect in that the child’s need for healthful food and physical activity is not being met. Not addressing the concern of obesity can constitute neglect, especially when a suitable program is available. In a 10-year study, children who were neglected (received little parent support) were sevenfold more likely to become obese as young adults than were children who were not neglected (Lissau & Sorensen, 1994).

Exposure to Environmental Hazards

The health risks associated with environmental hazards are firmly established. Hence, exposure to these hazards inside or outside the home is a form of neglect. Examples inside the home include poisonous substances and dangerous objects within easy reach of young children, smoking around children with pulmonary conditions (Gergen, Fowler, Maurer, Davis, & Overpeck, 1998), exposure to domestic violence (Sternberg, 1998) (see Chapter 10), and access to a loaded gun. Hazards outside the home include riding a bike without a helmet (Wesson et al., 2000), failure to use a car seat or seat belt (Stewart, 1997), and neighborhood violence (Osofsky, 1999). Exposure to lead may be a problem both in and out of the home (Tong, von Schniding, & Prapamontol, 2000).

Drug-Exposed Newborns and Older Children

The prevalence of maternal drug use during pregnancy as well as high rates of substance abuse among families of neglected children were mentioned earlier.
In addition, use of illicit drugs and being raised in a drug-using environment jeopardize children’s health and development.

The response to prenatal drug exposure varies. Chasnoff and Lowder (1999) describe responses ranging from inducements to engage in drug treatment all the way to criminal prosecution.

The use of legal but dangerous substances (e.g., tobacco, alcohol) during pregnancy also raises an important issue: Is such use neglect? Given our knowledge of the risks involved, it is probably not helpful to label use of these substances as neglect. At the same time, their use should be discouraged during pregnancy. Regarding older children, the risk of secondhand smoke, especially for children with pulmonary problems, is clear.

General Principles for Assessing Possible Neglect of Children’s Health Care

The heterogeneity of neglect precludes specific recommendations for assessing all cases. The following general principles are intended to help guide assessment. Given the complexity and possible ramifications of determining whether a child is being neglected, an interdisciplinary assessment is ideal, including input from all professionals involved with the family.

1. Verbal children should be interviewed. Possible questions include: “Who do you go to if you’re feeling sad?” “Who helps you if you have a problem?” “What happens when you feel sick?”

2. Do the circumstances indicate that the child’s need(s) is not being adequately met? Is there evidence of actual harm? Is there evidence of potential harm and on what basis?

3. What is the nature of the neglect? Is it medical, mental health, dental, or inadequate food?

4. Is there a pattern of neglect? Are there indications of other forms of neglect or abuse? Has there been prior CPS involvement?

5. A child’s safety is the paramount concern. What is the risk of imminent harm and of what severity?

6. What is contributing to the neglect?

7. What strengths/resources are there? Identifying strengths is as important as identifying problems.

8. What interventions have been tried and with what results?

9. Are other children in the household also being neglected?

10. What is the prognosis? Is the family motivated to improve the circumstances and accept help, or is there resistance? Are suitable resources, formal and informal, available?
General Principles for Addressing Neglected Health Care

This section summarizes general principles for helping in cases of neglected health care.

1. Convey concerns to the family kindly but forthrightly. Avoid blaming. A positive relationship is critical for effective intervention.

2. Be empathic and state an interest in helping.

3. Address contributory factors, prioritizing those most important and amenable to being remedied (e.g., recommending treatment for a mother’s depression). Parents may need their problems addressed before they can adequately care for their children.

4. Begin with the least intrusive approach, usually not CPS. For example, when faced with a child failing to thrive, an initial strategy might be to provide guidance on feeding and a suitable diet while closely monitoring the child’s growth.

5. Consider the need to involve CPS, particularly when moderate or serious harm is involved and when less intrusive interventions have failed. If CPS is to be involved, present this fact to the parents as a necessary step to clarify what is occurring and what might be needed and as a way to get help for the child and the family.

6. Establish specific objectives (e.g., diabetes will be adequately controlled) with measurable outcomes (e.g., urine dipsticks, hemoglobin A1c). Similarly, advice should be specific and limited to a few reasonable steps. A written contract with parents can be helpful.

7. Engage the family in developing the plan; solicit their input and agreement.

8. Build on strengths. There are always strengths that provide a valuable hook to engage parents.

9. Encourage positive family functioning. Videka-Sherman (1988) described the need to focus on building positive family experiences, “not just controlling or decreasing negative interaction.”

10. Encourage informal supports (e.g., family, friends, and fathers to participate in office visits). Informal supports are where most people get their support, not from professionals.

11. Consider support available through a family’s religious affiliation.

12. Consider the need for concrete services (e.g., Medical Assistance, Temporary Assistance to Needy Families [TANF], Food Stamps) (Saudia, 1981).
13. Consider children’s specific needs given what is known about the possible outcomes of neglect. Too often maltreated children do not receive direct services.

14. Be knowledgeable about community resources, and facilitate appropriate referrals.

15. Provide support, follow up, review progress, and adjust the plan as needed.

16. Recognize that neglect often requires long-term intervention with ongoing support and monitoring.

Advocacy Is Much Needed

Returning to the context in which neglect occurs, advocacy is needed at different levels: the individual child, parent, family, community, and society. Helping parents improve their children’s treatment is advocacy on behalf of children who are unable to express or meet their own needs. Acknowledging the stress a parent feels and facilitating help are also advocacy. Professionals are often in a position to recognize service gaps in the community. By partnering with advocacy groups, professionals can work to secure additional resources for families to reduce the likelihood of neglect or provide services for children who have experienced neglect. Efforts to strengthen families and support the development of community resources are also forms of advocacy. Enhancing access to health care illustrates advocacy at the broadest level. Each of these levels of advocacy is valuable in addressing the problems underpinning the neglect of children’s health care. In summary, professionals can play a pivotal role in ensuring children receive adequate health care and that they do not experience neglect.

Conclusion

Medical neglect can be a serious threat to children’s well-being. Professionals have an opportunity to collaborate with families and with other professionals and agencies to ensure that children receive adequate care. Preventing neglect by educating families about children’s health care needs and working with them to develop strategies for meeting those needs are critical roles for professionals.

References


Jehovah’s Witnesses of Washington v. King County Hospital, 278 F. Supp. 488 (Washington, DC, 1967), aff’d per curiam 390 US 598 (1968).


