Chapter 3

The Suffering of Children and Families

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In the usual and desirable scheme of events, there is no child without a family, just as there is no baby without a mother (31). Although this is not always the situation, most children, if they are to survive, live within a group of adults who provide some of the functions of a family. The child exists within the family, and because of the family. If the child suffers, so too does the family, and likewise the suffering of the family is echoed within the child.

When serious illness intrudes on any member of the family, some degree of suffering inevitably ensues, as death, the implicit or symbolic threat of death, and separation from cherished others imbue suffering with its unique qualities. The critical question is whether the suffering is overwhelming to the child and the family. The answer is forged by an interplay among the nature of the illness and the symptoms, the functioning of the family, the resources of the child, community support, spiritual beliefs, and the degree to which the health care professionals understand the suffering and provide helpful intercession and support.

The focus of this discussion is on the suffering that children and families endure because of medical illness and medical care, and on the steps that health care professionals can take to minimize (but not eliminate) the suffering. The concept of family will be used in its widest meaning; that is, a group of individuals, not necessarily genetically related, and of almost any conceivable size and composition, whose lives are intimately related functionally and emotionally.

Significance and Impact

Although medically related suffering has been addressed by many authors (7), (23), little has been written about the suffering of children or their families (10), (22), (11). The relative neglect of this crucial area unfortunately parallels the neglect of other areas concerning children and families. For example, many investigators have demonstrated that medically related pain in children frequently is either not considered or is underestimated, and is treated even less adequately than pain in adults (24). The manner in which pain is regarded and treated illuminates beliefs and behaviors regarding the larger issues of suffering (25). Cassell says, “Its relief—the relief of all symptoms—is the hallmark of care aimed at the relief of suffering.” [7, p. 245]. Most health care professionals recognize that children suffer as a result of medical illness and medical care. However, this recognition is often not reflected in priorities nor translated into actions.

Societal forces impinge on the awareness of children's suffering. In our society, children are particularly vulnerable to abuse. Furthermore, although our society places a high token value on the welfare of children, this value is not reflected in the spending of tax dollars, the establishment of effective intervention programs, the design of workplaces, or the prestige of people who choose to work with children. The medical arena is comprised of the same social fabric.

Suffering is addressed within human relationships, and the relief of suffering entails time and attentiveness, rather than high technology. If we assume that actual versus token priorities are separable by examining actions, then we see that the actual priorities of medical care are focused on disease and technology rather than on the relief of suffering. Given the social background, we cannot be surprised when medical suffering in children and families is not addressed with the same zeal as are other areas of medical care.

Although the relief of suffering has not held a high priority in the actual practice of medicine, children represent a particularly vulnerable population (21), and since children and their families are inextricably intertwined, the vulnerability extends to the family. The roots of vulnerability are manifold. Children are limited in their physical, cognitive, and communicative abilities, and carry little social power or prestige. Therefore, they are unable to act as their own advocates, and depend on others to do so (25). The extent of their suffering may not be heard or understood by adults, as their verbal communicative abilities are limited. We understand the suffering of others by communication and by empathy, and adults, by repressing or denying memories of their own childhood suffering, may not be empathic to the suffering of children.

When adults do hear and understand the suffering of children, the realization may be painful. One way to deal with this pain is to then minimize the experience. This defense is frequently and clearly seen in medical settings, when adults tell children or themselves that “it does not hurt that much,” or when they delete the awareness of the child's pain from their consciousness.

The concept of redemptive suffering runs deep in our society, and adults may rationalize suffering by assuming that it is for the eventual good of the child. The helplessness that adults feel when faced with a child's suffering is uncomfortable, and this discomfort is lessened by
When this is physical, we call it death. When this is emotional and relational, we call it trauma. Children are vulnerable to overwhelming suffering, or trauma. Similarly a family which is already vulnerable because of its particular composition and function is likely to disintegrate, or undergo trauma, in response to the overwhelming illness or death of a child. However, no matter what the strengths, all individuals and all families have a critical point beyond which suffering becomes traumatizing.

The fourth dimension of suffering is time. The longer suffering continues, the more unendurable it becomes, although the ability to endure is of course influenced by the other dimensions and by the resources of the individual, the family, and the system. Also, continuing suffering may erode the very strength that is necessary for endurance, thus contributing to disintegration. Time is particularly important when considering the suffering of children and families. Time is a relative rather than an absolute construct; a short time for an adult may be an eternity for a baby or a young child. Therefore, we, as adults, cannot apply our concepts of duration and endurability to children. Because children suffer so readily in what seem to us to be short times, and because the welfare of children and their families are intertwined, families too can suffer in what seem to be short times.

We can view suffering in families as being both an experience of the individual and an experience of the system. Ordinarily we do not think of systems as suffering. However, since the family system partakes of the experiences of all the individuals, but is in fact not reducible to these experiences, the individual suffering is expressed within a larger sphere, which for want of a better term we can call family suffering. The dimensions of suffering that apply to individuals—intensity, quality, impact, and duration—also apply to families. Similarly, the constituents of individual suffering—physical, emotional, social, cultural, and spiritual—apply to families.

Avoidable and Unavoidable Suffering and the Responsibility of Health Care Professionals

Pain and suffering are an integral part of human existence. However, some suffering is necessary and unavoidable, and some is unnecessary. Within this distinction, we can examine the concept of the redemptive
value of suffering, as it applies to children, and the responsibility of the health care professional.

Despite the best efforts of parents, politicians, societies, and health care professionals, much disease and trauma is unavoidable. Similarly, suffering due to medical illness, and to the potentially curative medical treatments and procedures used, is also unavoidable. No matter how supportive and compassionate the medical care, when a child is diagnosed with a disease such as leukemia, the family and the child will suffer with the threat of death. In such situations, although we can provide maximal analgesia and anxiolysis using pharmacologic, cognitive-behavioral, and psychological approaches, procedures such as bone marrow aspirations and lumbar punctures produce anticipatory anxiety and suffering over the possible results. No child would choose to have a bone marrow aspirate. No matter how much the health care professionals seek to cure and save children from death, some children will die, and they and their families will suffer. Such suffering is unavoidable.

Pain, distress, anxiety, and frustration are necessary to growth and development. When these experiences are tolerable and mild, the child does not suffer, and may gain strength as a result of the experience. For example, children fall and hurt themselves when they begin to explore the world. The child who is never hurt in this context is probably not exploring. The parents have the responsibility to make sure that the injury is not severe. If the parental response is appropriate, the child learns to tolerate and recover from minor injuries. Chemotherapy is necessary to cure childhood cancer. Although the medication may produce nausea, vomiting, fatigue, alopecia, and hospitalization because of fever and infection, the attendant suffering is necessary, if and when the chemotherapy is necessary.

If chemotherapy that had no symptomatic side effects was as effective as currently available chemotherapy, administration of the medication with the side effects would be as unthinkable as tripping a toddler so that she learns to tolerate falls and pain. In the treatment of disease and injury, as in the rest of life, when it is possible to reduce or avoid pain, anxiety, and suffering, without producing more suffering in the long run by these efforts, the health care professional must do so. Thus the health care professional is aware of all ways to minimize present and future suffering, and is sometimes forced to weigh present versus future suffering. For example, telling a child and her family that she has a serious and potentially life-threatening illness produces suf-fering. Talking in euphemisms or lying would decrease the immediate suffering, but with very deleterious long-term effects. However, giving the bad news without going slowly, allowing for hope, and providing privacy and support fulfills the requirement for truth telling, but produces unnecessary suffering. The health care professional is forced to simultaneously assuage and tolerate suffering. This can be a very difficult situation, as compassion and empathy must consistently be tempered with logic and objectivity, in a manner that is helpful for the patient, the family, and the health care team. Very different strengths and reactions must coexist.

When it is not possible to avoid suffering, the health care professional can almost always find ways to help the child and the family tolerate the experience without disintegration. In order for this to happen, the health care professional must be aware of, attentive to, and respectful of the sources of suffering for children and their families. Such attentiveness reduces the essential loneliness of suffering.

Sources of Suffering

Suffering has physical, emotional, cognitive, social, and spiritual components. These components can be heuristically separated, but in actuality are inextricably interrelated. For example, the parents of a sick newborn baby on a ventilator may be sitting immediately at the bedside. If, however, they are unable to hold the baby, the baby will experience the lack of holding in physical terms. Social isolation is emotionally deadling. Physical pain affects emotional well being.

Cultural forces affect all components of suffering. Conditions that produce suffering in one culture may not in another culture. Furthermore, helpful reactions to suffering are shaped by the cultural background of the family. Rarely is it beneficial to challenge cultural beliefs in the course of treating illness or injury, unless the cultural backgrounds or beliefs of the child and family differ, or unless the welfare of the child is in jeopardy. For example, some cultures believe that a person who is dead should not be mentioned, or that one should not talk about death with a dying person. When such beliefs are truly cultural rather than solely defensive, the family can be helped to support the child in its own way. A child is not helped by being in the middle of a cultural disagreement between the parents and the health care professionals.
In illness and trauma, the sources of suffering are often multiple. A baby in a neonatal intensive care unit may experience pain from multiple procedures, overstimulation from lights and noises, lack of restorative sleep, isolation from parents, lack of soothing and loving holding and touch, lack of oral stimulation except for noxious procedures, uncomfortable positions, rapid and jerky handling at unpredictable times, and a variety of other uncomfortable stimuli. A child with cancer could have pain, nausea from chemotherapy, lack of adequate and restorative sleep, separation from parents, worry about death, embarrassment over appearance, and lack understanding of the reasons for multiple procedures and hospitalizations.

The individual contributors to suffering may in and of themselves be large or small. However, the total outcome of suffering is simila to stress; stress can result from a single overwhelming stressor, or from the accumulation of multiple small hassles, or both. Although impending death, with all its suffering for the child and the family, may not be preventable, addressing the multiple smaller sources of suffering can do much toward easing the total burden for the child and the family. Additionally, the mere act of attentiveness to the small details of suffering reassures the child and family that they are not alone in their suffering—and that sense of a committed physician or nurse being with them is perhaps the most powerful force we can wield.

Suffering in Ill or Injured Children

The Need for Comfort

Pain is one of the most common causes of suffering in patients of all ages. Pain related to disease, medical procedures, and trauma in babies and children can be safely and effectively minimized, although not eliminated, by using a combination of pharmacologic, cognitive-behavioral, psychological, and physical interventions [5]. Chronic or recurrent pain unrelated to disease or trauma can be more difficult to treat, but the total suffering of the patient can be decreased using a combination of approaches.

Other symptoms also contribute to suffering. These include but are not limited to nausea, vomiting, constipation, fatigue, pruritus, lack of restorative sleep, dry mouth, and dizziness. Children may be unable to communicate these symptoms, so that careful assessment and a high index of suspicion are imperative.

However, these other symptoms, although very unpleasant, usually do not have the symbolic connotations of pain. Pain is experienced by children, adolescents, and adults as a metaphor for illness and death (10). Babies likely experience pain as undifferentiated badness coming from without, no matter what the source of the pain, and children up to the age of 12 (and often older) verbally express their understanding of pain as a punishment for their inner badness and wrongdoing (13). This conception of pain as a punishment may remain in the unconscious, as expressed in the Greek root word for pain, which means penalty or punishment.

Thus, the symbolic qualities add to the intolerable nature of continuing severe pain, as when an experience is construed as punishment for one’s badness, and suffering gains a new and tormenting dimension. Alternatively, the child (or adult) who consciously or unconsciously feels that punishment is deserved may not mention the pain to parents or health care professionals.

The Need for Attachment

Social connectedness is a vital requirement for all humans. For children, growth and development are adequate only if and when the needs for attachment are both met and maintained. When the early needs for love and attachment are not met, children starve emotionally and sometimes physically, becoming withdrawn, apathetic, and irritable (27), (4). Babies hospitalized in neonatal intensive care units after birth may never have their needs for attachment met.

Likewise, after an attachment with a parent has been formed, separation can be traumatic, especially if the environment is unfamiliar and full of noxious experiences and overstimulation. Abrupt separation from parents is akin to abandonment in the experience of a young child. A 16-month-old toddler who has surgery and emerges from anesthesia in a recovery room without a familiar person present has no way of knowing that she will be reunited with the parent in a few hours. The terror and disorientation may overwhelm the child’s tenuous ability to soothe and comfort herself. Although the parents have not in fact abandoned the child, the child’s experience is what we need to consider.

The effect of separation on the child will be determined by age
his little brother. Children need the protection of their parents, and worry that if their parents are too overburdened, they will not be able to continue their role as protectors. Children may also be angry at their parents for "allowing" the illness to occur, and then in their conflict over that anger seek to protect the parents.

Usually children are not directly aware of the substance of these worries and guilty, and feel only confused and driven unless they have the opportunity to explore their concerns. This process may be heightened if the parents (and the health care professionals) are indeed too burdened by their own reactions to tolerate the child’s feelings.

A clinical example of the protection of the parent is that of a 4-year-old boy with terminal neuroblastoma. He was noted to be consistently lying very still in his bed, not playing or sleeping well. However, the child did not cry, and when asked said he did not hurt at all. His mother knew intellectually that he was dying, but expressed the belief that his tumor was still responding to chemotherapy. She believed he was not playing or moving because he was tired. On careful assessment, when given an outline of a child’s body, and asked to color in his pain using colors he had chosen, the patient colored the most severe pain in a pattern that reflected his ultrasound and CT scan—i.e., going down the spine, with twigs radiating into the legs, which presumably were sciatica. As he drew his pain, his mother watched. Initially she appeared surprised and distressed, but then was able to listen and allow him to express his pain.

In retrospect, the child knew from past experience that pain represented disease and caused distress and sorrow in his mother, and he was protecting her from this knowledge and himself from her reaction. The boy was given analgesics for his pain, and was playing the next day. He and his mother were able to continue talking about his pain, and his mother began to accept that he indeed had progressive disease. He died comfortably two weeks later.

Another situation that interferes with the parent’s ability to provide comfort and protection for the child is the common practice of asking parents to aid in physically restraining their children during painful or distressing procedures. Under no circumstances should a parent be asked to do this, unless it is for a brief hug to hold the child during a routine procedure such as an immunization or venipuncture. Parents should be with their children during procedures [1], [5], but their role is to comfort, not to force and restrain. Guiding the parents in this role also reduces the suffering of the parents, as they need to
comfort and soothe their children. This increases their own sense of control. When parents are forced to restrain their ill children for painful procedures, they may cope by becoming angry at the child for struggling. This response is not helpful for either the child or the parent.

For example, a 3-year-old girl had anxiety-provoking and mildly painful procedures scheduled about every four weeks for a skin condition. The procedures lasted about fifteen minutes. The author observed the child during one of the procedures. The child became frightened and started crying before going into the procedure room. In the procedure room, she was placed in a restraining device, but due to the nature of the procedure her arms had to be free. Her father was asked to hold her arms still, while the nurse held her head.

The child screamed and struggled during the entire procedure. Initially the father was gentle and careful while restraining her. However, after about five minutes, his face became grim and angry appearing. In response to the child’s scream, “Let go, let go, you’re squeezing me!”, he responded by yelling at her, “If you would just stay still I would not have to squeeze you.” The situation deteriorated from there.

This is not an unusual situation; parents cannot be expected to be supportive and reassuring while restraining a screaming, struggling, sweating child. The guilt and sorrow over seeing one’s child suffer changes into anger at the child; if the child would not struggle so, the situation would not be so difficult.

The primary intervention in this situation was to change the roles and interactions among the physicians, the nurses, the parent, and the child. Additionally, pharmacologic and cognitive-behavioral strategies were suggested.

Children and families fear being alone with their experiences, fears, and concerns. Community support can buttress the family in its struggles. However, especially in extended or serious illnesses, the health care professionals become vital figures in minimizing isolation. The role of physicians and nurses as powerful and beneficial supporters should not be underestimated. Even when the contents of the burden of suffering cannot be altered, the felt presence and caring of the physician or nurse actually decreases suffering. Children over the age of about three may feel this as acutely as adults. A 6-year-old with cancer, who awakens with stomach pain while in the hospital, may be better able to settle and relax after the physician examines her, pronounces that the pain is from the chemotherapy and not from anything dangerous, and tells her and her parents that a medication will be given in just a few minutes to help with the pain. Obviously, the reaction of children to physicians and nurses varies with their past experiences. Some chronically ill children are frightened of white coats and the laying on of hands.

Physicians unwittingly may avoid visiting children who are dying in the hospital. However, the maintenance of daily attentive visits is as important for the children as for the parents. Even though the physician may know that nothing medical is gained by listening to the child’s heart and lungs and feeling her pulses, the examination provides an opportunity for touch, and is experienced as a demonstration of caring. Finally, even when a child is comatose, health care professionals must continue to speak as if the child hears and understands every word. This may be the reality, and parents gain solace in the thought that their dying or comatose child may indeed be able to hear them speak or feel their touch. One of the exceptions is when a child is neurologically brain dead, based on careful examination and EEG. In these situations, acting as if the child can hear and understand breeds false hopes in the parents.

The Fear of Death

Fears of annihilation, mutilation, and death are ubiquitous. Even before children cognitively comprehend death, they fear annihilation. For example, babies react with what appears to be terror and then rage to a sudden drop or change in position. After the age of 15 to 18 months, fears of mutilation become significant, and serious illness and medical procedures almost always elicit these fears. Mutilation fears can be very concrete and specific throughout childhood. As they are often unrelated to adult conceptions of physiology and reality, these fears may not be understood or elicited. For example, a 3-year-old child may react to the words “we are going to take your blood” with abject terror, as she visualizes her body as a container filled with blood being drained of all its essential inner contents. The fears of annihilation and mutilation persist in inchoate and often unconscious forms through adult life.

By about age four, children become aware of the more cognitive concept of death, building on their previous experiences of separation and fears of mutilation and annihilation. Children’s conceptions of death reflect their cognitive development, and probably do not approach adult form until the school years. Nevertheless, although a 5-year-old may not understand death as we do, she still knows that people and
animals die, that death involves separation, that it causes great grief, and that she could die. She may also understand that adults do not like to talk about these things.

Children frequently feel very alone in their fears and fantasies of mutilation and death. Young children are cognitively unable to separate fantasy from reality by themselves, and unexpressed fears become powerful terrors. Because adults are viewed as powerful and knowledgeable authorities, accurate information expressed simply and concretely can do much to allay children's fears and fantasies. However, parents, because of their own fears, may be unable to talk with their children about these matters. The children sense the parents' fears, and keep their thoughts to themselves.

Often health care professionals contribute to this communicative isolation. The professionals have their own fears of death, especially when a child is involved, and may not be able to talk with the children or help the parents to do so. Explicit and implicit collusions among health care professionals and parents to withhold information from children are not uncommon in medical settings. Parents cannot be expected to know how to talk with their children in unusual situations of serious illness. However, health care professionals must be able to intercede.

At the same time, giving a child too much information or forcing a child to talk about subjects that she wishes to avoid can be hurtful. The type of information given must be adjusted to the age and personality of the child. Too little information can inflame fantasies, and too much information, especially if it is not given with an awareness of developmental issues, can inflame fears and shatter defenses. Denial, when used in moderation, is valuable. No one can contemplate their own death or the death of a loved one constantly. Reprieve is necessary.

Children who lie in their hospital beds without diverting activities may be forced into melancholic withdrawal, as their defenses are overwhelmed by contemplation of reality and fantasy. Children must be provided with play and art activities. A hospitalized child can be brought into the hallway or the playroom during the day, so that she is exposed to social interactions. Art therapy, play therapy, video games, taped recordings of stories, and television are useful in the child's room. Metaphors, stories, art work, and imagery help reticent and fearful children work through difficult issues slowly, safely, and at their own pace. Specialized personnel are usually not necessary to provide such interventions, as parents can be guided in providing appropriate activities. Such guidance helps parents feel less helpless and more in control.

The Need for Control

Starting early in the second year of life, all humans require a perception of control over at least some aspects of their environment. The extent of actual control varies with age and situation, but removal of a previously established level of control is felt keenly, and undermines self esteem. We suffer and rage over that which we feel we cannot control. Illness is usually not controllable, and intrudes despite all efforts. In addition, hospitals tend to remove control over personal tasks and decisions from patients and families [10], [22].

Control over life and death is not usually possible, but control over smaller issues can be preserved. However, the preservation of control may require a modification of hospital routines and expectations. The extent of children's control must be appropriate to their age and development. Too much control is alarming, too little is enraging. Children and families can help in planning daily schedules, regulating analgesia [14], [20] and symptom control, keeping track of symptoms, and performing daily hygiene and tasks.

The Need for Visibility

Children are at times treated by health care professionals as if they were invisible. For example, physicians may address the parents and not the child. Physician's rounds may be held in the hallway, within sight of the child and the parents, but without including them in the conversation. Nurses may talk to coworkers at the bedside, ignoring the child. During procedures, physicians and nurses at times deal with their own anxiety by engaging in jokes and banter. Children report outrage over this practice, especially when the conversations are "over their heads," or jokes and innuendoes are made without including the child in producing the humor. The sense of being invisible is deeply disconcerting for individuals of all ages, especially when they are trying to maintain their sense of self-wholeness in the face of serious illness.
The Need for Validation

The lack of validation or a direct contradiction of a child’s expressed subjective experiences is a source of considerable anger and confusion. This problem is frequently seen in the assessment of pain, when the child is told that the pain is not as bad as she says, or that it is “in her head.” Patients of all ages with chronic pain are often told that the pain is “in your head,” and the first part of any effective treatment consists of dealing with their anger and confusion over these statements. The patient knows that the pain is in her body, hears the statement as pejorative (which it often is), and then secretly wonders if maybe she is “crazy.” The physician, in making the statement, may be stating her assumption that emotional factors are maintaining or influencing the pain, but is unable to communicate the interplay of emotional factors with pain in a positive manner, and in effect cancels the patient’s experience and concerns.

Health care professionals can choose to disagree with patients and families over treatments and interpretations. However, subjective experiences are the property of the person experiencing them. Challenging or contradicting the experience erodes the boundaries between individuals, and makes no sense intellectually, emotionally, or therapeutically. Children are particularly vulnerable to such invalidation, as they tend to question their own sensations and perceptions. Lack of acceptance of inherently subjective phenomena results in either a withdrawn and confused child, or a child who exacerbates her symptoms in an attempt to gain belief.

The Need for Quiet

Overstimulation is often a problem in hospitals. The environments are full of lights, noises, beepers, interruptions, fragments of conversations, disruptions of sleep, unusual odors, large machines, and hospital personnel scurrying in and out of rooms and past bedside. Humans of all ages require times of quiet and restoration, especially when they are ill. In adults, the overstimulation of the intensive care unit can lead to a transient psychosis. We must consider what the same environment does to babies, who are unable to clearly communicate their inner states.

To avoid suffering or self-fragmentation, babies and children require some sort of reprieve from the onslaught. As in many situations,
tend to internalize. The emergence of anger and irritability after a long and debilitating illness is often a sign of recovery. Too often in health care settings, children’s behaviors are equated with inner experience. In reality, behavior is a complex amalgam of inner experience, cultural mores, temperament and inherent coping style, learned responses, emotional resources, adult reactions, and degree of debilitation. Behavior tells us how a child copes, not what she is feeling. Many children who suffer do so quietly, but are quite willing to relinquish their burden to a trusted person.

Suffering in Families

Before we discuss the suffering of families, the function of the family must be examined. Families provide many functions for their members. The functions vary depending on ages, inner strengths, and outer circumstances. Although a family can be understood as a system, the individuality of each member should not be lost in the system, although the extent to which the individuality is either prized or subsumed into the system varies among families and cultures. What is helpful for a family in one culture is not necessarily helpful in another culture.

Physical and emotional protection of the members is one function of the family. The same actions may result in overprotection for one member of the family, and underprotection for another. The degree to which protection is helpful also varies over time for each person. Families provide and meet needs for connectedness and continuity. One hopes that the primary emotion felt within families is love. However, even in the most well-functioning families, a web of complex, ambivalent, and highly changeable emotions exists. The family provides a place where children and adults experience intense love, hate, rage, jealousy, loss, and other emotions, all of which provide connectedness. The well-functioning family provides safety and protection of self and others within this web of emotions. Another function is communication, which may be verbal or nonverbal, cognitive, and emotional. Families ensure survival. Every member of the family has a pragmatic function, however that function is observed. Even young children help with simple household chores. Support is vital to the cohesiveness of a family. Even family members who fight constantly with one another unite in defense when the attack comes from without. Families provide a trial ground for activities, interests, and pursuits. A parent considering a career change will usually talk this over with other family members before making a decision. Similarly, children will practice for school performances within the relatively safe arena of home. The family is the teaching ground for relationships, ethical values, and spirituality. Even though adults may choose different paths and values than their parents, nevertheless their thoughts and choices are inevitably influenced by the early environment and teaching. Finally, the family is the model for the larger community. A child exists first within a dyadic relationship, and then moves into a more complicated system with multiple family members. Many larger group and political processes consist of the same forces—love, hate, jealousy, power, loyalty conflicts—that exist within a family.

All the functions and properties of a family interact, as do family members (even when the interaction is in purposeful avoidance). Additionally, all factors impinging on any individual also impinge on the whole system. One can examine the functions of a family, and see how the serious illness and suffering of a child would affect or possibly erode every one of these functions. The separation of a child from the family for hospitalization is painful for the other members of the family. Siblings, in addition to missing their brother or sister and worrying about his or her welfare, may feel guilty because they previously had wished vehemently for such a possibility. Grandparents have their own special relationships with their grandchildren; these relationships are often disrupted by severe illness. Grandparents may be called upon to act as parents, or may feel excluded from the decision making.

Hospitalization and illness often stretch a family to its limits, with one parent staying at the hospital and caring for the sick child, and the other parent (if there is one) taking on all the burdens of the rest of the family. Emotional energies are taxed, leaving little available to communicate effectively among family members and to provide for regulation of the web of family emotions (10), (22). Sexual relationships between spouses may be disrupted, and generational boundaries blurred. When children are hospitalized for long periods of time, and a parent stays with the child, that parent may begin to consider the hospital as the family. Illness and hospitalization disrupt family rituals. Financial resources may be expended, and work placed in jeopardy because of numerous absences to care for the child, leading to fears of all family members about the survival of the family.

The death of a child is felt by all families to be unnatural. Death and the process of dying leave the family and its members with ever-
present scars, even if the open wounds heal. Making reparations and saying goodbyes is necessary but difficult. Parents and siblings usually have guilt—guilt of omission and commission, and guilt that are based in reality as well as in fantasy. These guilt may not need to be addressed directly or explicitly, but somehow each member of the family must come to terms with these feelings. Siblings especially may have a difficult time, as they are often relatively and unavoidably neglected during the illness of the patient, and they are riddled with intense jealousy and guilt.

Children who die live on in the memories of the survivors. If the child dies in pain and anguish, this will be the memory of the family, even if it is never spoken. Therefore, optimal intervention for pain and suffering is crucial, not just for the child as she is dying, but also for the other family members and their memories.

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**Developmental Considerations**

In order to understand and assuage the suffering of children, we must understand their cognitive, emotional, and social development. This discussion focuses particularly on preverbal children, as health care professionals often find it easier to understand the suffering of children who can express themselves verbally.

**Babies**

The primary need of babies is to be loved and protected. Babies crave and require human contact, expressed by touch as well as by sight, sound, and smell. Physical protection and emotional love are interdependent. If one loves a baby, but has no physical contact, that baby will not feel loved. Babies have no way to understand the reasons for pain. Therefore, all pain, whether inflicted via a lifesaving medical procedure or inflicted as abuse, is equally anguishing (8). For older children and adults, understanding the meaning lying behind pain helps make the difference between bearable and unbearable pain. Such is not true for a baby.

Babies can tolerate short periods of pain and other distress. For example, immunizations cause pain and distress, but cannot be thought of as causing suffering. Suffering in a baby occurs when an event exceeds the capacity of the baby to relatively quickly reintegrate and settle,

given adequate comforting. Taking routine immunizations as an example, if babies are held, rocked, and fed after the procedure, they usually calm within 10 or 15 minutes. However, if the pain and distress should continue, the baby's immediate terror and rage, as expressed by crying, eventually subsides, and the baby becomes irritable, restless, apathetic, or withdrawn. After a certain point, babies no longer respond readily to soothing intervention, and are in a state of disintegration.

Unfortunately, babies' responses to overwhelming suffering may not elicit the necessary responses from health care professionals and other adults. As babies disintegrate, they gradually stop crying and exhibiting other signals of distress. This leads adults to conclude that the baby is adapting and coping. Babies may lapse into sleep not because they have dealt with the experience, but as a way of escaping an intolerable situation or intolerable emotions. This leads to less concern and comforting, which further perpetuates the cycle.

An example is that of a baby who has been chronically and painfully abused physically. Such babies often cry little in response to events such as venipunctures and intramuscular injections—a very different response from the baby who does not expect pain to be a part of life. Health care professionals who are not familiar with the behavior of abused children may mistakenly interpret the behavior as being due to a calm temperament (which is possible, but not the only explanation).

Since babies are not verbal, traumatic experiences are not later communicated verbally to parents or other adults. However, data support the retention of nonverbal memories, which later permeate social interactions and intrapsychic events, and may appear in dreams, nonverbal memory fragments, or play (19), (30), (26), (3), (16), (28), (17). Since the nonverbal communication of previous trauma is often not understood by adults, this leads to the common misconception that experiences that are not (verbally) remembered and communicated are of no or little significance. The lack of access to the experience leads to an underestimation of the degree of suffering of babies and of the impact on future structure.

The parents also suffer when a baby suffers. Few parents are able to watch their baby experience pain without feeling anguish themselves. Even witnessing an immunization can be difficult for parents, although most are able to deal with their reactions by remembering the consequences of not having the immunization. We want parents to experience distress themselves at the thought of their baby's distress. A lack
of response in a parent may be an indication of inadequate empathy and bonding. Loving parents also want to be with their babies, and to hold their babies. Separation may be as difficult for a parent, albeit experienced in a different manner, as for a baby. Even the hospitalization of a baby for a few days, although routine for a health care professional, can evoke anguish in the parents. Likewise, the inability to touch a very ill baby can be tormenting for the parent and grandparent. Health care professionals whose babies become ill and require hospitalization or an unusual procedure are often surprised by the vehemence of their reactions when they see their baby undergo the same procedure that they themselves may have performed with little thought on many other babies.

**Toddlers**

Toddlers have some verbal skills, and can understand simple directions and reassurances. They are acutely attuned to the responses of the parents to guide their own responses, and are beginning to understand that people who go away do come back. They intensely desire control and autonomy, and are fearful of separation. Their sense of time, like babies', is very different than that of an adolescent or adult, and a short period of continued pain, distress, or separation evokes disintegration, manifested as irritability or apathy. Toddlers have no concept of death, but they do fear mutilation, as anyone who has watched a toddler's response to a scrape or cut can attest. However, these fears can be assuaged with familiar rituals, such as the loving application of a band-aid. Toddlers generally value rituals—the rituals of bedtime routines, accompanying their parents to predictable places, being given particular food for meals. Interruption of these routines can be very disturbing, as it invokes the fears of separation and loss of control.

Thus the circumstances of illness and hospitalization are sources of suffering for toddlers. They need their parents as much as babies, although a transitional object such as a blanket or stuffed toy may suffice for a while. Although rituals cannot be completely maintained as the context and environment are changed, part of the ritual may bolster the toddler's sense of continuity and security. Parents should be allowed and encouraged to be present at all possible times. Because the toddler reacts to the parent's response, parents may benefit from guidance. For example, during a procedure a parent can sit by a toddler's head, talking softly, stroking her cheek, telling simple favorite stories.

**Preschool Children**

Preschoolers understand simple explanations, and benefit from preparation for potentially distressing events. In addition, they are beginning to formulate their own explanations for events. These explanations revolve around themselves, and preschoolers often assume that distressing events are punishment for their actions. They are able to accept and respond to other explanations. Preschoolers are developing a sense of time, and can tolerate distress for longer than younger children. However, their limits are still much less than for adolescents and adults.

Preschoolers have also absorbed the cultural mores of the parents, and this may alter their willingness to communicate pain and suffering. For example, a 3-year-old child from Vietnam was hospitalized for a serious injury of her leg, which was assumed to be very painful. The health care professionals gave her morphine, but were unable to completely assess her response, as she and her parents spoke no English. The child was lying quietly, not crying or moaning, but the health care professionals arranged for an interpreter. The interpreter ascertained that the child's pain was indeed well controlled, but that she had severe pruritis from the morphine. However, her parents had told her not to scratch, and so she did not. In many other cultures, such obedience to the parents' commands would not be observed.

**School-Aged Children**

School-aged children are able to understand some consequences, and to have a more formed conception of the future. Rituals continue to be important, but can be varied more than for the younger child. The school-aged child seeks meaningful explanations, and such explanations are often helpful. The school-aged child is often very aware of emotionally regressing during serious illness, and may feel ashamed of the regression.

**Adolescents**

Adolescence is a stormy time, during which a child grows into an adult sexually, cognitively, emotionally, socially, and spiritually. The changing body habitus, along with growing social awareness and awareness of sexuality, make body changes due to illness very difficult to tolerate.
The school-aged child may tolerate alopecia from chemotherapy in a much more sanguine fashion than the adolescent.

Loss of control and independence are particularly difficult for adolescents, who are already struggling with separation, individuation, and autonomy. Adolescents must be part of the medical decision making, although the decisions cannot be theirs alone. Like school-aged children, adolescents regress during illness, and may benefit from reassurance that bringing a stuffed animal to the hospital is perfectly fine. Continued or profound regression is a sign of trouble. The ill adolescent may be very troubled by existential concerns. Because the adolescent is establishing her independence from the parents, she may need, far more than younger children, to be able to confide in someone outside the family, such as a family friend, favorite teacher, or guidance counselor. Ill adolescents may feel socially isolated, and support groups can help even reticent and shy youngsters to express their concerns.

Conclusions

Children suffer as much as, albeit differently than, adults. Health care professionals who care for children carry the responsibility to assure that suffering as much as possible. In order to do so, the professionals must be aware of the multiple sources of suffering for children and families, and of how they may contribute to that suffering. This requires a concerted and continued effort, as the easiest way to deal with the suffering of children is to minimize or not notice. Also, health care institutions are organized around the roles of the health care professionals, and not around the comfort and emotional well-being of the patients. Within such environments, individuals may become discouraged, and feel that they can do little. However, such is not the case. Small acts can make a large difference in the total burden of suffering. The easing of a few parts makes the whole more tolerable. An individual's concern and presence imbibes patients and families with the sense of not being alone.

In order to effectively help children and their families, health care professionals must deal with their own suffering. It is not easy to watch a child suffer or die, and health care professionals may protect themselves in ways that are not helpful to themselves or to their work. They may become desensitized or "burnt out" and not recognize or heed the suffering of others. The suffering may be denied in a futile quest to prolong life at all costs. Anger at the situation may be projected onto other patients or families, or one's own self, family, or coworkers.

It is inevitable that these protections against unspeakable loss will affect all of us at various times in our careers. However, we can do much to help one another by sharing our distress and conflicts with other health care professionals. It is when we struggle with our anguish by ourselves that we run the greatest risk of engaging in behavior hurtful to ourselves and others.

I would like to recount a dream I had as a third-year pediatric resident. This dream delineates the suffering of health care professionals on several levels. The dream occurred during a brief sleep while "on call" for the oncology service.

I was giving chemotherapy to a 9-year-old boy with cancer. (He was the same age as one of my own children.) After I gave him the chemotherapy through his IV, he turned into a tiger. I was horrified at what I had done. The tiger ran from the room, and I ran after him, but could not catch him.

He ran to the River Styx, jumped in, and began to swim across the river. I looked at the water, which was full of flotsam and jetsam. I did not want to jump into the water, so I looked for Charon with his boat, but Charon was nowhere to be seen. In desperation, I jumped into the water and swam after the tiger, for someone had to rescue him.

At that point, my dream was interrupted by a nurse calling to tell me it was time to give chemotherapy to one of the patients. I slammed the phone down without answering, but then as I emerged further from sleep realized what had happened and walked to the nurse's station.

Since this behavior was uncharacteristic of me, after I administered the chemotherapy I told the nurses my dream. One of the nurses, a warm and supportive woman, later gave me a picture of a tiger, which I keep to this day in my office.

References