Armfuls of Time: The Psychological Experience of the Child with a Life-Threatening Illness

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Key Words

Pediatric palliative care · Child psychology · Child psychiatry · Bereavement

Abstract

The seriously ill or dying child, his/her parents, and siblings all face daunting challenges. The services of a multidisciplinary team are required for optimal care. Experts in the fields of child psychology, psychiatry, and/or pediatric palliative care should be included in this team. Different aspects of the care take into consideration the role of the child in the family, the impact of the diagnosis on the child, loss of control and the threat of these losses. These have to be addressed to ensure an optimal psychological outcome for all concerned, irrespective of the eventual survival or demise of the sick child.

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Introduction

I just wish that I had armfuls of time. (4-year-old child) [1, p. 11]

The metaphorical image of longing for ‘armfuls of time’ exemplifies the extraordinary challenges faced by the seriously ill or dying child. These children live with many levels of awareness, and their pain and suffering, both physical and psychic, can be great.

I felt much better because I had someone to talk to all the time! Every boy needs a psychologist! To see his feelings! (6-year-old child) [2, p. 3]

As pediatric palliative care develops into a field of its own, there is a window of opportunity to define the parameters of optimal psychological care for these children. The fields of child psychology and psychiatry, as well as other mental health disciplines, provide specialized knowledge and skills. Their specific interventions include: evaluation of the child’s psychological status, diagnosis of psychological/psychiatric symptoms and disturbance, psychotherapy and psychotropic medication, consultation with members of the family and the professional team looking after the child.

Because the availability of psychological consultation and treatment is often limited, or ‘outside’ the cultural context of care, the challenge is to provide thoughtful emotional support for the child in a carefully planned manner. One must take into account the child’s need and expressed wish for such support beyond the family, as well as the level of comfort that the child has formed in relationships with members of the team (or one particular individual). Emotional support comes in many forms, from an openness to listen and answer questions, to regular visits at expected times, to creative art and play activities that allow the child expression of feelings and concerns.

The Child in the Family

I have a closer relationship with my family than most other kids because I’ve needed them more these last years. (11-year-old child) [1, p. 87]

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The child-in-the-family is a unit unto itself, with its own distinctive identity, strengths and vulnerabilities. The child's ongoing struggle to withstand and integrate the trauma of illness unfolds within this framework. His or her ability to cope is greatly influenced by the family – the individual and collective responses of its members. Under optimal circumstances, the family affords a refuge in which the child can replenish psychic resources, shielded from the battering assault of the illness. The myth that a child's life-limiting illness either unites or destroys a family reduces complexity to oversimplification: resilience and vulnerability play out in complex ways in these extraordinary circumstances.

Sibling relationships are a crucial axis in the family, a subsystem of their own [3, 4]. All too often, the positive caring and devotion between the patient and siblings is underestimated and overlooked. Most children demonstrate an impressive capacity for concern about one another, even when ambivalence intensifies under the stress of illness. Although the healthy siblings live the illness experience with the same intensity as the patient and parents, they often stand outside the spotlight of attention. In the following section, a 16-year-old sibling comments:

Everyone in my family was always calling [and asking], 'How's [your sister] doing?' ... No one ever asked about me. No one cared anymore. ... From that point on, everyone always cared about [my sister] and it made me feel like no one cares about me just because I'm not the one who is physically sick. [5]

Professionals in the field of pediatric palliative care now articulate a strong mandate to focus on the siblings in their own right, both in the present and preventively for the future. These children will live the rest of their lives marked by the experience of profound loss – or threat of loss – at an early age.

The Impact of the Diagnosis

When I heard that I had leukemia, I turned pale with shock. I was scared of needles, blood, of seeing all the doctors, of what was going to happen to me. I was MAD about a lot of things: staying in the hospital, taking medicines, bone marrows, spinal taps, IVs, being awakened in the middle of the night. I was sad that I didn't have my toys and that I was missing out on everything. I felt lonely and cried about not being at home and not being able to go outside. I also felt hope: getting better, going home, eating food from home, and seeing my friends. (8-year-old boy) [1, p. 31]

This child articulates the shock; the fear of everything from the concrete medical procedures to the sudden possibility of an altered future ('what was going to happen to

me'); the constellation of sadness, grief and loneliness of separation, and the absence from his normal life. Accompanying all these feelings is a forthright statement of hope. Other feelings cited by children include pain, terror, embarrassment, and shame. All these words attest to the overwhelming onslaught of new and frightening experiences that must be quickly assimilated.

Such is the 'irreversibly altered reality' [2, p. 45] into which the child is catapulted by the diagnosis. Regardless of which aspects of life may appear unchanged, in fact, nothing is the same. The diagnosis thus stands as a dividing line, a marker of 'before and after' and ruptures the continuity between the past, present and future. The child, who garners security from predictability, and whose sense of time and timing is not yet well anchored, is thrust into a world of uncertain contingencies. This inability to take time for granted represents a crucial loss of innocence during childhood.

Children's awareness of the implications of their illness can be conceptualized along a continuum [1, 6]. At one end, the child acknowledges being 'very sick' or having a 'bad disease'; however, there is no prognostic statement referring to life or death. In the middle, the child expresses some awareness that his or her life might be in jeopardy – uncertainty about *living* – but without a focus on death. At the other end of the continuum, the child is explicitly conscious that he or she could die of the illness. Awareness is a fluid, not a static state and is gleaned from many sources. Primary is the 'wisdom of the body': the child's irrefutable recognition of how sick he or she is. Other cues include the child's knowledge of the illness, the urgency and intensity of treatment, the emotions of family and caregivers, and encounters with other patients.

A 10-year-old sibling expressed her reaction to her younger brother's diagnosis, reflecting many of these shared concerns and fears:

I feel scared and sad – as if I don't really know what is happening. At first my parents just told me that my brother needed an operation. They didn't say it was cancer. I feel confused – just all mixed feelings – I don't know what to think. I don't really have a lot of hope right now, but maybe just a little. ... Angry and mad: Why him? Why did it have to happen to him? I feel like I am hearing a lot of mixed messages because I have all of these different feelings and everyone is telling me different things. Like they say mostly that he is going to be okay, but they – and I – don't really believe it. [7]

The field of pediatric palliative care is challenging, in that the child may play a role in decision making about the transition to palliative care, thus, about life and death

issues. A 7-year-old girl told her parents: 'I'm too tired to fight anymore. If I have to continue suffering, I would rather be in heaven.' These statements were major determinants in the parents' choosing a palliative care plan without any further experimental treatment for her [1, p. 116].

Loss and Anticipatory Grief

Loss of control and relationships – and the threat of these losses – are a part of these children's reality. A pivotal issue, not to say fear, is loss of control: over their bodies, over illness and pain, over emotions, over the passage of time, and ultimately over life itself. Loss of relationships – expressed through fears of separation, absence and death – is paramount in anticipatory grief, the experiential process which reflects the anguish of threatened loss. It is thrust into being at the time of diagnosis, and ebbs and flows throughout the course of the illness. While the prognosis for many diseases can now be presented with new optimism, the subjective experience of receiving the diagnosis still connotes death.

When I first heard my diagnosis, one question kept going around and around in my head: 'How long do I have, Doc?' (12-year-old child) [1, p. 114] (fig. 1)

In the following two drawings, the inward grief for self, and the testimony to the family's grief are illustrated and articulated.

A 9-year-old boy portrayed his older brother as a rock singer, his mother cooking, another brother, his father and his pet hamster. When asked what had changed after his diagnosis, he added tears to each person. With regard to the omission of himself he explained: 'I didn't include myself, because at the time I was in the hospital, and didn't think I'd be back in the picture' [1, p. 34]. The little hamster imprisoned in the cage may well be his symbolic self-representation. Thus the boy graphically conveyed his own anticipatory grief (fig. 2).

An 8-year-old boy hastily drew stick figures to illustrate the members of his family. One brother was playing baseball, another was playing hockey, and the patient himself was bald, and was not doing anything; neither were the parents engaged in any activity. When asked what changed in his family after he became ill, the boy immediately scrawled: 'They all cry' [1, p. 35]. This is a striking portrait of anticipatory grief within the family system (fig. 3).

Fig. 1. How long do I have, Doc?

Fig. 2. I didn't think I'd be back in the picture.

Fig. 3. They cry.

Longing for Normalcy

At the same time that the child is living with the 'abnormal' presence and perils of illness, they long for the normalcy of daily life.

If kids are normal, not sick, they like to be treated special. But if kids have a disease, they wanted to be treated normal. (11-year-old girl) [1, p. 82]

From looking, to feeling, to being normal, the concept has implications for children's sense of competence and self-esteem. Parents have a formidable challenge from the outset in learning to treat their child as 'normally' as possible in this extraordinary life situation. Yet, their ability to do so communicates a critical message to the child: while the illness is abnormal, he or she is still normal in their eyes.

School as the defining structure of every child's day-to-day life represents normalcy, a consistent and stable routine. Children understandably express apprehension about if and how their peers will accept them: will they tolerate 'differentness'? Some children convert what could be the 'stigma' of their condition into a badge of courage and fascination. It is not uncommon for children to maintain two categories of friends: those from the 'healthy' world of school and neighborhood, and those from the hospital and clinic. Children who share the experience of illness demonstrate profound caring and empathy for one another. The threat of loss lurks, and when a child dies, the other children's grief has an acute poignancy.

The Child Who Is Dying

The distillation of anticipatory grief to its essence marks the imminence of death. At times imperceptibly, at other times dramatically, the child who has been living with the illness is transformed into a dying child. As the child confronts impending death, he or she may show signs of preparation. The child's actions or words are often quite matter-of-fact; their significance is not necessarily elaborated.

A 7-year-old girl had a recurrent dream:

In the dream, I want to be with my mother, and I can never quite get to her.

The girl recounted the dream in a joint therapy session with her mother. Whereas the mother found the dream 'excruciating', her daughter stipulated that 'even though the dream is very sad, it's not a nightmare.' The dream

eventually provided the focal image for mother and child to work through the anticipatory grief process [2, p. 70].

The endpoint of the terminal phase is often marked by a turning inward on the part of the child. Their cognitive and emotional horizons may narrow, as they conserve all their energy simply for physical survival. A generalized irritability is not uncommon. The child may talk very little, and may even retreat from physical contact. Although such withdrawal is not universal, a certain degree of quietness is almost always evident. The child is pulling into him or herself, not away from others. If the parents understand this behavior as a normal and expectable precursor to death, they do not interpret it as rejection. They must be reassured that their contribution to the child's care and comfort – and most of all, simply their presence – are now the essence of the child's world.

Your brother or sister will always be in your heart. (8-year-old bereaved sibling) [8]

Bereavement follow-up by the professional team is an intrinsic component of comprehensive pediatric palliative care. Families often express the sentiment of a double loss: first and foremost, the loss of their child, as an individual and as a member of the family and the greater community. Second, compounding their grief and disorientation, they mourn the loss of their 'professional family' – the treatment team whom they have known and trusted, often over months and years. Contact from a team member after the child's death not only assuages the family's sense of abandonment; it can serve a crucial preventive role by identifying families at particular risk for serious psychological, social, emotional and physical sequelae.

Thank you for giving me aliveness. (6-year-old child) [1, p. 167]

Giving children 'aliveness' – vitality in their life for however long that life may last – is the essence of pediatric palliative care.

Conclusion

The services of a multidisciplinary team consisting of experts from child psychology, psychiatry, and/or pediatric palliative care are necessary to help the seriously ill or dying child, his/her parents, and siblings. Approaches to care should recognize the role of the child in the family, the impact of the diagnosis on the child, and the realization of loss of control to ensure an optimal psychological outcome for all concerned.

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