

# Virtual Mentor

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### Trusting Them With the Truth—Disclosure and the Good Death for Children with Terminal Illness

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Discussing a child's imminent death with him or her is a terribly painful idea. Ronald Dworkin has written that there is something we feel to be particularly tragic about the "waste of life" involved in the death of a child:

The death of an adolescent girl is worse than the death of an infant girl because the adolescent's death frustrates the investments she and others have already made in her life—the ambitions and expectations she constructed, the plans and projects she made, the love and interest and emotional involvement she formed for and with others, and they for and with her [1].

This understandable feeling that a child's death is a waste naturally deters us from considering how to make it as "good" as it can be—the idea that it could be positive at all is more than distasteful.

Other emotions, desires, and circumstances give justifiable pause: the desire to spare the child pain and avoid impairing the quality of what life remain, the parents' own grief, the uncertain prognoses and mixed goals [2] that differentiate pediatric care from that of adults, and lack of knowledge about what children know and understand. Also, as Lawrence Wolfe, MD, says, "death" is "a word that, in our society, can be synonymous with evil, contamination, and darkness," and it is instinctual to want to protect one's child from these horrors [3]. In many cultures (one article describes that of China), it is highly taboo to speak openly of a patient's terminal status in his or her presence (but there are implied, customary ways of acknowledging the imminent death) [4]. A Western version of this idea manifests itself in the concern that informing the child will cause him or her to "stop fighting" for life. In America's culture of by-the-bootstraps self-determination, belief in the power of positive thinking—and its implied corollary, the infectious danger of "negativity"—is a cultural force to be reckoned with.

On the surface it may seem that young children's understanding of death is so limited that talking to them about it might only confuse, or worse, pain them, but evidence appears to suggest (Kreicbergs et al. cite two [5, 6]) that it is beneficial for the family to talk openly about the child's approaching death. It is important to do this, in a developmentally appropriate way, to allow the child the possibility of—as disturbing and even offensive as this may seem when first applied to children—a "good death."

### **Does Talking about Death Help?**

One much-referenced study examines this idea through the experiences of the parents of children who died of cancer. Kreicbergs et al. surveyed the parents of Swedish children who had died of terminal cancer between 1992 and 1997 and found that those who discussed the child's imminent death had a much less complicated bereavement process and less regret than those who did not [7]. More specifically, 27 percent of those who did not talk about death with their child regretted that choice. Among parents who sensed their child was aware of his or her impending death and did not talk about it, nearly half regretted not having done so (a much higher incidence of regret than reported among parents who did *not* sense that awareness and did not talk about death.) None of the parents who talked with their child about death experienced regret about having done so. The authors point out that eligible parents who declined to participate in the survey may have regretted talking about death, though no evidence points in that direction. These results from parents who, we presume, have some grasp of their child's emotional "best interest" imply that if the child knows or suspects he or she is going to die it is more important to acknowledge it than it is in cases where the child does not know or suspect.

But are dying children aware of their condition? Little is known about the kids' experiences; widespread reluctance to conduct research on children in general and (understandably) children with terminal illnesses in particular has hampered further study. The limited research available indicates that in many cases, they do. It is believed that the experience of a terminal illness hastens emotional and cognitive maturation [8]. And, of course, an observant child gleans information from caregivers' and relatives' behavior, medical treatments, and other patients, but, as Barbara Sourkes puts it, the primary source "is the 'wisdom of the body': the child's irrefutable recognition of how sick he or she is" [9].

In the face of this irrefutable knowledge, attempts to protect through nondisclosure may be detectable to the child. Surveys [10] have shown that families and patients are sensitive to the trustworthiness of their caregiving team and perceive mixed messages and incongruously positive "spin" as insincere. It is not unreasonable to assume that at least some children have a similar ability to see that their parents or caregivers are sweeping something under the rug; as Kreicbergs et al. put it, telling children the truth may enable "their inner lives...and the outer world...to become congruent, thereby preventing frustration" [11]. (Of course, this doesn't necessarily prescribe a particular method or degree of explicitness. There are less overt ways of acknowledging approaching death, as in the Chinese customs discussed above, that may be effective without being unnecessarily traumatic.)

### **(How) Will They Understand?**

How does one have such a conversation with a child? For the youngest and oldest children, of course, it is easier to determine what is developmentally appropriate, but what of the gray area in between? What do the kids know and what should they know?

In their study of the young children's knowledge of and fear of death [12], Slaughter and Griffiths conclude that talking about death with children (not particularly dying children, but children in general) in biological terms (i.e., what happens to the body) may help alleviate their fear of it [13]—though of course, there is no word on whether it will help them with grief or sadness.

The authors could not determine whether more knowledge of death tends to increase fear (as children realize that death will happen to everyone they know, including themselves) or to decrease it (by helping them understand it as an explicable and natural phenomenon) [14]. But it stands to reason that children who are dying are bound to experience this fear at some point, and informing them stands a chance of decreasing it, in addition to providing them with other benefits, which are discussed below. A low level of prior knowledge about death need not deter the parent from discussing the topic; just because children may not already fully understand the immediate biological causes of death, they are not necessarily incapable of grasping that information—and, more importantly, what they cannot or do not grasp may not be germane to their emotional processing of or coping with their *own* death.

### **Why Is This Important?**

Of course, merely knowing what is cognitively suited to the general population of children of a given age doesn't make breaking bad news to an actual child any easier to figure out or to do. But there are truly important reasons to discuss death with dying children. One less-often discussed reason is keeping kids from being deprived of the opportunity to make their deaths meaningful. For the reasons already mentioned, the “good death” is a possibility that, in Western society, is open to adults, but is rarely extended to children. This need not be the case.

The good death is generally thought to include some combination of choice, dignity, comfort (freedom from pain), preparation for death (saying goodbye, avoiding the unwanted prolonging of life or treatment) and leaving a legacy. As Liben et al. write, the good death is about maintaining hope (not for life, but for meaning, comfort, enjoying what is left of life, and so on) during the dying process. Parents must be careful not to make the mistake of equating acknowledgment of death with robbing the child of hope—even hope for a cure, which, it is becoming known, can coexist with acknowledgment of coming death and may even be an optimal coping mechanism [15]. Loss of hope for extended life in no way impairs hope for a meaningful life and a good death [15, 16]. Children are capable of finding meaning in their deaths [3]—and that meaning tends to have a surprising amount to do with altruism.

In an area of study largely comprising interviews with parents and caregivers, Hinds et al. investigated the priorities of dying pediatric cancer patients themselves, as expressed in recently made end-of-life choices. They interviewed 20 patients between 10 and 20 years old at St. Jude's Children's Research Hospital in Memphis, Tennessee, and Sydney Children's Hospital in Sydney, Australia, who had recently made one of three end-of-life decisions: enrolling in a Phase I trial, putting in place

DNR orders, or discontinuing cure-directed therapy to focus on symptom management only. The children in question were cognizant of their terminal status and participated actively in the decision-making process. The choices were their own. The interviewers questioned the patients about their reasons for choosing as they did. Eighteen of the subjects remembered all the options given; all subjects remembered the options they had chosen and understood that the consequences of the choice were likely to include their own deaths.

Next, the interviewers inquired about what they refer to as the factors patients considered in their decisions, which is to say, what mattered to them.

By far the most reported priorities—mentioned by 19 of the 20 patients—were relational or altruistic in nature, defined by the authors as “decision making affected by caring for others (family, staff, future patients), preferences of others, and the desire to benefit others” [16]. Eleven of those patients (55 percent of the subjects) specifically mentioned wanting to help unknown others (i.e., future patients)—as the authors put it, this “was not anticipated and is not reflected in existing theories of child development” [8]. Further, “several adolescents in [the] study sample referred to their decision as their chance to do something good for someone else; one referred to his decision as his final gift to his parent” [8].

And that’s precisely the point: though a child’s legacy doesn’t generally include the kinds of things we typically think of as legacies, such as leaving behind children of one’s own, making a mark in an industry or profession, or leaving money to people or causes, the leaving of a “medical legacy” by participation in research to benefit future patients, or of a personal legacy is still eminently possible—Wolfe recounts what he calls an unexceptional (which is to say, not uncommon) story of a 9-year-old patient who carefully gave away cherished possessions to friends and family as a way of preparing for death [3]. And, as Hinds et al.’s study shows, kids are strongly motivated by those possibilities—and should be given the chance to act on that.

## Conclusion

Parents and caregivers may hesitate about if, when, and how to broach this topic with dying children because of their deep care and respect for the child. But to give dying children the opportunity to have some control over, and make some meaning from, the inevitable is to afford them the utmost respect: telling them the truth and trusting them with it.

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