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Children Facing Death: Recurring Patterns of Adaptation (Revised)

Deborah E. Greenham

Roger A. Lohmann

This article examines a number of recent studies on adjustment problems faced by dying children. Particular attention is given to the relationship between growth and development and the child's awareness of their impending death. Two principal topics connecting research with clinical practice will be examined in this article: the research on awareness contexts translates into the clinical issue of whether or not to tell children of their impending death. Likewise, the question of how immature children who are dying cope with their impending death and their understanding of the effect it will have on others.

Emotional growth and situational adjustment are primary concerns in much recent research on death and dying. Social workers who work with the dying are generally familiar with Elizabeth Kübler-Ross's account of the gradual and progressive emotional acceptance of death. She suggests a sequence of five stages – denial, disbelief, victimage (“why me? woe is me.” feelings), rage and a final stage of acceptance. She argues that this sequence explains not only the inevitability of one's own death, but also acceptance of the death of others (Levy, 1976, 79-93). Glaser and Strauss describe the typical patterns of relations between the dying and their significant others in terms of “awareness contexts” which they say can be open, closed or suspected and may involve mutual pretense, based on the degree of communication involved and acknowledgement of the reality of death (Glaser & Strauss, 1965). In this study, an awareness context is defined as “the total combination of what each interactant in a situation knows about the identity of the others and his own identity in the eyes of the other.”

Much of the best-known research literature on death and dying, including the two studies mentioned above, is based on and most applicable to, emotionally mature adults. But, what about deaths of children who don't have the emotional maturity or the full range of social skills that the Kübler-Ross stages or the Glaser-Strauss awareness contexts point to? Few human experiences are more shattering than the death of a child. Many social workers, like most other adults, fear the emotionally shattering impact of allowing themselves to see, hear and respond to the behavior of a dying child, which seems to awaken one of the deepest fears of humankind – the fear of death before the fulfillment of a life fully lived.

Until recently, the conventional, widespread assumption among many assumed that children understood death as a reversible event and that they did not recognize the concept of mortality (Levy, 1976, 81). Probably this view was derived from

observations from child's play, where those who "die" are seen to collapse, remain still and then arise again and rejoin the play. In the Glaser-Strauss terminology, it was assumed that children have a type of closed awareness – that they have not yet reached the stage of maturation in which they are able to deal with the powerful emotions related to death – and that efforts to disrupt this "nature order" could prove emotionally damaging to the child. Recent research on dying has begun to spell out more clearly the complex relations between personal development, situational factors and the acceptance of death among children. Much of this research has been done with young terminally ill cancer victims, although presumably many of the conclusions also apply to children dying of other causes.

Acceptance of the implications of this recent research for social work practice with dying children offers support for certain well-accepted procedures, but there is still a need to readjust certain time-worn notions. Two principal topics will be examined in what follows: the research on awareness contexts translates into the clinical issue of whether or not to tell children of their impending death. Likewise, the question of how those who have not yet achieved maturity cope with their impending death and their understanding of the effect it will have on others.

To Tell Or Not Tell?

Until the early 1970s shielding young patients from the knowledge of a life-threatening disease was probably the norm among all helping professionals (Kaplan, 1973). For the most part, this was just a question of when children really can understand death. Solnit and Provence reflected a widely held view in suggesting that a child's concept of death does not crystalize until adolescence (Ross & Klar, 1982, 148). If this were so, then it would not be helpful to tell preadolescent children they are dying, mostly because the information would have little significance for them. However, as continuing concern over this issue implies, young children do, indeed, develop their own (however limited) understanding of their own and others' deaths. Several research studies make this clear. As reported by Levy, Robert Fulton used word association, response times and galvanic skin tests to determine a pattern of increasing emotional involvement with "death words" by children between the ages of 5 and 15 (Fulton, 1977; Levy, 1976). Anthony found several distinguishable levels of linguistic understanding between the ages of 3 and 13 among English-speaking children. These ranged from ignorance to clear, logical or biological definition (e.g., the understanding that death involves the cessation of brain function). These findings closely parallel those of Piaget with regard to the developmental concept of causality: By age 5 or 6 children attach a definite meaning to the word death, and by age 8 or 9, almost all children use a causal-logical explanation to some degree. Thus, it is both theoretically plausible and empirically likely that most children achieve some "realistic" understanding of death, both emotionally and cognitively at an early age and that their concept of death is already well developed long before adolescence. The idea that children cannot or do

not understand death is only a valid rationale for not telling children about their impending death in the case of extremely young children (e.g., those under age 5).

A more open approach to this question began to gain ground in the late 1960s and early 1970s, after it was discovered that terminally ill children are often aware of their prognosis even if they are not told, and that secrecy often sets up a circular process (in both children and adults) in which the necessary evasions and deceptions of significant others and caregivers erodes trust, provokes excessive fear, withdrawal, anxiety and frustration. For those children old enough to have even a primitive conception of death, the burden of evidence and contemporary opinion seems to support "open illness," that is, telling the child and confronting the matter openly (Levy, 1976, 72).

Those who are still skeptical will ask: but how will children deal with this information? One approach to this question is the intellectual-cognitive approach suggested by the previous reference to Piaget. Not only should children be informed that they have a fatal illness but they should also be encouraged to turn to caregivers for answers to the inevitable questions. For example, after knowing and understanding their conditions, Vernick and Karon (1965) found that children's tension levels were significantly lowered. They also found in a subsequently study that most children were actually relieved to openly acknowledge and discuss their serious concerns about death (Karon & Vernick, 1968). In the absence of encouragement, children may actually come to believe that if they openly express fear of death, further contact with others may be lost (Waechter, 1971). Death may be considered an inappropriate topic of conversation with adults, but Bluebond-Langor (1978) argues that children may interpret it as their responsibility to give emotional support for others (including adults) in such circumstances. Children are capable of selecting their behavior to affect the ways others see them.

A second approach combines the cognitive with the emotional: William M. Easson, for example, argues that children's reactions to their dying and death depend on their level of understanding and emotional maturity (Easson, 1970). Children begin to deal with approaching death as they become aware of the necessity of doing so, and they are then able to respond with the unique strengths that children have. Easson links children's understanding of death with their development of self-awareness and identifies five developmental stages that children undergo in their understanding of death. In the first stage, infants have no understanding; only the physiological reflexes that strive to maintain life. During the second state (which Easson dates from 5 months to two years), children's reactions to their own deaths is influenced by the physical processes that produce death. They react not only to the discomfort and pain they feel but also to the anxiety of their parents. By the third stage (3-4 years old) children already begin to understand that they have a separate physical existence and emotional identity. As a result, they begin to recognize and deal with feelings of being and nonbeing. By the fourth stage (4-5 years old), Easson says, children's understanding of their diagnosis becomes a function of intellectual growth and training. Full

understanding of the diagnosis and of its implications for them and their significant others is possible by this point. By the time they reach the fifth stage (usually be ages 5-7 years old) children are able to grasp abstract concepts, understand the meaning of present and future time and become progressively less able thereafter to avoid the full meaning of their death.

Such development is not serial and unilinear, however. Both the normal interruptions and setbacks experienced by other children and by other dying patients, and the special, poignant regressions of the dying affect these children. Leyn noted that as death approaches, preschool aged children may, at times, regress to emotional levels at which they no longer feel that they are independent but rather that they and their parents exist as a unit, and thus the children will survive (and even live forever) (Leyn, 1976). Such a reaction, it should be noted, may well be the particular reaction of small children to the more general reaction of denial. With older children, the growing realization of their anticipated death, as noted by Easson, and the concomitant link to deals of being and non-being, combined with the emergence of a sense of self also brings with it the growing realization that dying means separation from loved ones.

Expanding (And Shrinking) Social Worlds

Bluebond-Langor links cognitive and emotional events with the emerging social matrix of children. She conceptualizes children's acquisition of information about their world and their place in it as a socialization process occurring simultaneously with the dying process (Bluebond-Langor, 1978). She finds that many dying children have a greater understanding of their circumstances than they may reveal to the adult world and that their decisions not to reveal their awareness reflects their unique knowledge of the social order to which they are being socialized, and an understanding of what it means to die "a proper death" in their society.

Like many other authorities on this subject, Bluebond-Langor attempts to capture the dynamic, unfolding events of a child's death by using a "stage model" which breaks an action or event into clear, discrete stages in sequence. However, her approach is unique in that she links the progressive stages as experience, information and self-evaluation of children. It is the question of concrete information, she argues, that brings about adjustments in the self-concept of dying children. Without the requisite knowledge of their situation, children cannot integrate new information or come to new conclusions about themselves and their worlds.

Bluebond-Langor argues that children with leukemia pass through five stages in the acquisition of information, while simultaneously passing through five different conceptions of themselves. In the first stage, children learn that leukemia is a serious disease. Much the same could be expected with other, similarly serious, potentially fatal illnesses. At this time, they may begin to accumulate additional disease-related information; e.g., about drugs and their side effects. They voluntarily inform people of their new identity as "sick". At any point, they may

begin to exhibit lesions and explain to others how seriously ill they are. Through feedback, they gain confirmation in this transition of their new identity from others' reactions to them. They will probably hold this image of themselves as sick until they receive evidence that they may be getting better. Particularly important in this regard is confirmation of their improvement from their peers; other children with leukemia and their parents.

Passage to the second stage requires the experience of remission of symptoms and the discovery of the relationship of medication and recovery. Bluebond-Langor observed that children with leukemia carried on long, detailed conversations at various times with other hospitalized children with similar experiences. However, shared information is only synthesized into a reorganization of thoughts and feelings by a relapse. Whenever a relapse occurs, adults tend to speak less openly with child patients, answering as few questions as possible. In any case, staff members in hospitals and clinics tend to give only brief explanations, usually at concrete, descriptive levels, for what they are doing. They seldom talk about the implications and they avoid extended interaction with child patients. This explains in part why and how children with comparable experiences turn to one another for information. In this stage, children who are dying begin to observe and understand the taboos of disease and death.

The third stage is marked by an understanding of the purposes and implications of special procedures that may be used to administer medications and additional types of treatment that may be required to deal with side effects. With recurrent relapses and complications of medications, the child patient's sense of well-being begins to fade. As their world becomes increasingly hospital-centered, they become increasingly aware that they are different from other children.

In the fourth stage, child patients come to view their illness as a permanent condition. They view themselves as always sick, never getting better. They may put treatment, procedures and symptoms into larger perspective and see the full cycle of relapses and remissions, realizing that medications do not last as long as they are supposed to and that their peers share with them not only the same experiences but the same fatal prognosis. It is only on receiving information of the death of a peer, however, that these children come to realize that the cycle of recurrent relapses and remissions cannot continue indefinitely and eventually ends in death.

This fifth and final stage brings with it the realization that there is only a finite number of medications, and that when these medications are no longer effective, death is inevitable. Children in this stage often express awareness of their prognosis – directly and indirectly – in their conversations and by the kind of reading, art and play they are interested in. It also impacts their view of time and their behavior toward others (Natterson & Knutson, 1960). Their concerns and anxieties about their welfare are poignantly revealed in their questions about other children who have died. Vernick and Karon note that although children apparently accepted evasive answers to their questions, the attempt to deceive was never successful with children between the ages of nine and twenty (Vernick & Karon,

1965). Such deception likely prevents the development of empathic bonds between these children and adults. The children then tend to remain silent, outwardly accepting adults' lies but inwardly feeling threatened.

Easson notes that when a peer death occurs each child on the ward may become part of a group denial process (Easson, 1970). These child patients learn not to be outwardly disturbed when another patient disappears from their midst and doesn't return. Each parent works with the others to support this denial and to maintain this necessary façade.

The child-patient's personal experiences, Bluebond-Langor argues, are the critical factor in the passage through these various stages ((Bluebond-Langor, 1978). Disease related experiences, including nosebleeds, bone pain, and injections become the basis for gathering new disease-related information, which then becomes the raw material for the reworking of the child-patient's self-concept. Clinics, hospitals and other places where opportunities for interaction with peers are possible are the locales for gathering such information on what is happening.

The experience of having a life-threatening disease allows children to assimilate information by relating what they see and hear to what they feel and think. Ill children seldom ask about things that are not happening to them. Thus, the experience of being socialized to their illness and its implications is of central importance for them. Experience also explains why (except at the extreme youngest ages) age and intellectual ability are not related to the speed or completeness with which children pass through various stages of awareness. Some three and four year olds of average intelligence with extensive disease-related experience know more about their prognosis than very intelligent nine year olds who are still in their first remission or have had fewer clinical experiences and are aware only that they have a serious illness.

Bluebond-Langor also notes that the time lapses between stages tend to be experienced based and the same for most children regardless of age. Passage from the first stage to the second occurs rapidly for everyone upon relapse. Passage through the second, third and fourth stages takes somewhat longer, and there is an indefiniteness about these three stages in general. However, passage to the fifth stage often takes place immediately upon the child learning of the death of another child, and all knowledge from previous stages is quickly synthesized into this new self-awareness.

Conclusion

One of the most devastating themes in the entire literature on death and dying is the "open awareness" dilemma that dying children face. Even though the evidence clearly suggests that dying children are typically aware of their terminal condition, acknowledgement of that awareness can bring with it the threats of social ostracism and emotional abandonment by parents, caregivers and significant others who may find the added emotional burdens of the child's awareness unbearable.

Bluebond-Langor observed children who saw their own task in life as providing emotional support for others. By acceding to the adult's wishes to maintain an atmosphere of mutual pretense, these children hope to keep the parent-child and caregiver-patient relations from breaking down. They respond to the pattern of social order and to the apparent personal needs of others with whom they are in contact, and thereby gain or maintain feelings of social worth. Such social worth, in turn, allows them to feel more like normal children and to act as if they have a future. By reinforcing the hopes of the adults around them, they guarantee the continuous presence of those adults. In this way, they allow their caregivers to practice reciprocal roles. In ordinary circumstances, parents are responsible for nurturing, protecting and rearing their children, but these ordinary tasks become impossible in the face of terminal illness. As a result, parents often feel pressured into pretense. And physicians are similarly able to salvage their self-esteem in the face of losing a patient, and able to continue to work with dying children by engaging in mutual pretense.

When children sense that parents and physicians are lying to them, they are likely to lose confidence in trust in these adults (Zeligs, 1974). Karon and Vernick note that if physicians act to prevent children from gaining realistic knowledge of the disease in its terminal phases, the usual result is the progressive emotional withdrawal of the staff from the children, almost as if the children had already died. Zeligs believes that it is the journey toward death, and not the moment of death, that is most frightening to children, and that children forced to cope with a conspiracy of silence are forced to die a thousand deaths. By contrast, if the staff and parents have instilled feelings of confidence in the child, they will be able to draw emotional support from these same relationships in their final days. Consequently, much of the published literature speaks of the marked tendencies toward partially closed awareness and mutual pretense among dying children. Presumably, the extent to which this tendency prevails is related to the child's level of social development, with older, more mature, children far more likely to engage in this practice than younger ones.

Research studies with dying children strongly suggest patterns of relationships between the growth and development of the dying child, the level of awareness of the child to their dying, and the children's emotional and social handling of the reality of their own death. Because a growing number of social workers deal regularly with this problem, further investigation of the implications for social work practice of these research findings is needed.

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