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Children Facing Death: Awareness, Development and Terminal Illness¹

Deborah E. Greenham
Roger A. Lohmann

Abstract

This paper examines a number of recent research studies on the dying child with particular attention to the relationship between growth and development and the child's awareness of his/her dying condition.

The twin themes of emotional growth and situational adjustment have emerged as primary concerns in much recent research on death and dying. Most social workers concerned with death-related practice are familiar with Elizabeth Kubler-Ross's discussion of the cycle of unfolding emotional acceptance of death. She suggests five stages, which are typically labeled denial, disbelief, victimage, rage and acceptance as describing the pattern of acceptance of the reality of one's own death, as well as grieving for the loss of another (Kubler-Ross, 1969; Kubler-Ross, 1971). At the same time, Glaser and Strauss (1967) have described for different patterns of relations between the dying and their significant others in terms of *awareness contexts*, which they say can be closed, suspected, mutual pretense or open depending upon the degree of communication and acknowledgment of the reality of dying.

Both of these studies and much of the rest of the better-known literature on death and dying is based upon and most applicable to work with normal, emotionally mature adults. The question inevitably arises – what about death among children, who have not yet matured emotionally or developed the full vocabulary of social skills which the various awareness contexts require? There are few human experiences as shattering as a child's death. It appears that social workers, like most adults, fear the shattering impact if they allow themselves to see, hear and respond to a dying child's behavior. For the death of a child seems to awaken one of the deepest of human fears: the fear of death before fulfillment.

Until recently those who care for children have assumed that children understand death as a reversible event, and do not recognize their own mortality (Gogan, et. al., 1977). In other words, a type of closed awareness was assumed: Young children had not yet reached a stage of maturational readiness for dealing with the powerful emotions related to death and that efforts to disrupt the natural order could prove harmful to the

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child. Recent death-related research has begun to spell out more clearly the complex relationships between personal development, situational factors and the acceptance of death among children. Much of this work has been done with young cancer victims, although presumably many of the same conclusions would apply to children dying of other causes as well.

Acceptance of the implications of this recent research for social work practice with dying children offers both support for certain well-accepted practices and the need to readjust certain hoary, time-worn notions. Two principal topics will be examined in this paper: 1) the question of awareness contexts raised by Glaser and Strauss, which frequently translates into the clinical issue of whether to tell or not to tell the child of his² impending death; and 2) of the question of how those who have not yet achieved maturity cope with deal for themselves and others.

To Tell or Not To Tell?

Until the 1970s, shielding the young patient from the knowledge of a life-threatening disease was probably the norm among helping professionals (Toch, 1964; Solnit & Provence, 1963). In part, this was simply a matter of when a child really does understand death. Solnit and Provence reflected a more widely held view when they suggested that a child's concept of death does not crystalize until adolescence (Solnit & Provence, 1963). If this was so, then it would appear to be rather meaningless to tell pre-adolescent children that they were dying, since the information would have little meaning for them.

However, as continuing concern over this issue suggests, younger children do, indeed, develop at least limited understandings of their own and others' deaths. Several research studies make this clear: Fulton (1965) used word association, response time and galvanic skin tests, for example, to determine patterns of increasing emotional involvement with death words between the ages of five and sixteen. In an early study, Anthony (1940) found five distinguishable linguistic stages between ages three and thirteen among pre-war English children. These ranged from total ignorance to clear, logical or biological definition. Her findings, in fact, closely parallel those of Piaget on the developing concept of causality: by age five or six definite meaning is attached to the word death and by age eight or nine, a causal-logical explanation is used to some degree by nearly all children. Thus, it would appear likely that some understanding of death, both emotionally and cognitively, appears at an early age and is well developed in almost all children well before adolescence. Thus, inability to understand fails to provide a meaningful rationale for not telling for any but the youngest children.

Belief in the child's lack of conceptual understanding was a primary motive for the protective view, advising parents to shield their dying child from the realization of the

² The masculine pronoun was used throughout the earlier published version to refer to children of both genders. Here, the terms s/he and his/her are substituted.

severity of his/her illness and supporting efforts to make a sense of normalcy by cheerfully assuring the ill child that s/he will be well.

Beginning in the 1960s and continuing through the following decade, an open approach continued to gain ground as it was realized that terminally ill children are often aware of their prognosis even if they have not been told, and that secrecy often sets up a circular interaction process in which the evasions and deceptions of parents and caretakers erode the ill child's trust in others and can provoke excessive fear, withdrawal, anxiety and frustration

For those children old enough to have at least a primitive conception of their own death (*more on this below*) the overwhelming burden of evidence and contemporary opinion seems to support open awareness; that is, telling the child (Gogan, O'Malley & Foster, 1977; Natterson & Knutson, 1960; Binger, et. al., 1969; Spinetta, 1972; Spinetta & Maloney, 1975; Waechter, 1971; Furth, 1974; Kalnins, 1977).

But how will the child deal with this information? One approach to this question is the intellectual-cognitive approach suggested by the reference to Piaget above. The child should be informed not only that s/he has a fatal illness, but also encouraged to turn to caregivers for answers to questions. Vernick and Karon (1965) found, for example, that after knowing and understanding their condition tension levels in children were significantly lower. They also found in a later study that most children were greatly relieved to discuss their serious concerns about death (Karon & Vernick, 1968). In the absence of encouragement to discuss their condition, the child may come to believe that if s/he expresses fear of death openly s/he may lose human contact or suffer other dire consequences (Karon & Vernick, 1968). Or death may be considered by a child to be an inappropriate topic of conversation with adults. Bluebond-Langor (1978) argues that a child may interpret the situation as his/her responsibility to support others emotionally through the ordeal. Children are capable of choosing behavior in order to affect the way others see them and do so in that case.

A second approach strives to combine the cognitive with the emotional. Easson (1970) argues that a child's reaction to his/her own dying and death depends totally on his/her level of understanding and emotional maturity. A child will deal with impending death in the manner s/he best comprehends the task and responds with their own peculiar strengths as a child. Easson links the understanding of death in particular with the development of self-awareness and identifies five developmental phases in understanding of personal death by children.

For the infant, there is no understanding, only the physiological reflexes which strive to maintain life. During the second state, which Easson dated from five months to two years, the child's reaction to his/her own death is influenced by the actual physical processes that produce his/her death. S/he reacts not only to discomfort and pain but also to the anguish of his/her parents and caregivers. By the third stage, which emerges between ages three and four, the child is beginning to understand his/her separate

physical and emotional identity and, as a result, beginning to recognize and deal with feelings of being and the possibilities of non-being. By the fourth stage, emerging between ages four and five, Easson states that the understanding of the diagnosis is a function of the child's intellectual growth and training. Both an understanding of the diagnosis and of its implications becomes possible. By the fifth and final stage, between ages five and seven, the child is able to grasp abstract concepts, comes to understand the meaning of time present and time future, and becomes progressively less able thereafter to avoid the full meaning of their own death.

Such development is not serial and unilinear, however. Both the normal interruptions and setbacks also experienced by other children and the special, poignant regressions of the dying affect these children. Leyn (1976) noted that as death approaches, the pre-school child may regress to an emotional level where s/he is no longer an independent person, coming to feel that s/he and his/her parents live as a unit and thus s/he will live forever.

Such a reaction, it should be noted, may well be the particular reaction of the small child to Kubler-Ross's denial stage. With older children the growing realization of death noted by Easson and its linkage to ideas of being and nonbeing, and to the emergence of a sense of self also brings with it the growing realization for the child that dying means separation from loved ones.

The Expanding Social World of the Child

Bluebond-Langor (1978) pushes our understanding one step further by linking cognitive and emotional events into the emerging social matrix of the child. She treats the child's acquisition of information about his/her world and his/her place in it as a socialization process. In her research, she found that many children have a greater understanding of death than they reveal to the adult world, and that the decision not to reveal their awareness reflects each child's unique knowledge of the social order into which they are being socialized, and their individual 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 actively dying by using a stage model. However, her approach is also unique in that she links together experience, information and the self-evaluations of the child. It is the question of concrete information, she argues, which brings about adjustments in the dying child's self-concept. Without this requisite information, children can't integrate new information and come to new conclusions about themselves and their social worlds.

Bluebond-Langor argues that leukemic children pass through five states in the acquisition of information and that they concurrently pass through five different self-conceptions. In Stage One children learn that "it" (leukemia) is a serious illness. At this time they may accumulate information about drugs and their side effects. They inform people of their new identity as "sick", exhibit wounds and explain to others their own assessment of how sick they are. They gain confirmation in this transition of identity through the reactions of others to them. They will hold this view of themselves-as-sick until they see evidence that they are getting better and have confirmation of this from their peers (e.g., other leukemic children) and their parents.

Passage to Stage Two requires the experience of treatment, remission and discovery of the relationship of medication and recovery. She observed leukemic children at various stages carrying on long, detailed conversations about this with other children. However, shared information is only synthesized into reorganized thoughts and feelings by the occurrence of a relapse. When this occurs, adults speak less openly with children, answering fewer of their questions. Staff members in hospitals and clinics give only brief explanations for what they are doing at a concrete, descriptive level never going into the full implications and avoiding extended interaction. At this stage, children begin to realize and observe the taboos of disease and death.

The third stage is marked by the understanding of the purposes and implications of special procedures such as injections, surgery, radiation and chemotherapy, that may be used and additional treatments that may be required to deal with side effects. With recurrent relapses and complications from medications, a child's sense of wellbeing may begin to fade. For some children, there may be little or no freedom from pain and increasing awareness that they are different from other children. The child's world becomes increasingly hospital-centered and less home-centered.

In Stage Four, illness becomes viewed as a permanent condition. Children view themselves as always sick, never getting better. They may now put treatments, procedures and symptoms into larger perspective and comprehend the full cycles of relapses and remissions. They now realize that medications don't last as long as they are supposed to and that they share with their peers not only similar experiences but also similar prognoses.

It is only on receiving information of the death of a peer, however, that these children realize that the cycle of relapses and remissions does not continue indefinitely, and frequently end in death. This final stage brings with it the realization that there are only a finite number of medications, and when these are no longer effective, death may be inevitable. Children in this stage often express awareness of their prognosis directly or indirectly in their choice of topics of conversation, reading, art, play and in their view of time and their behavior toward others (Natterson & Knutson, 1960). A child's concern and anxiety about his/her own welfare may be poignantly revealed in the question "What happened to Johnny?" Vernick and Karon (1965) noted that any evasive answer to this question received superficial acceptance by children but was never believed by any of them in the 9-20 age group. They noted that this prevented the development of meaningful relationships between these children and adults. The children became mute, outwardly accepting adult's benign words of falsehood but in other ways showing signs of feeling threatened.

Easson (1970) noted that each child on the ward he studied became part of a total group denial process whenever a death occurred. They showed no signs of being outwardly disturbed when a member of the patient group disappeared and never returned. Instead, each patient appeared to work with the others to support this denial and maintain its necessary façade.

Bluebond-Langor (1978) argues that experience is the critical factor in the passage propelling movement through these various stages. Disease-related experiences such as nose-bleeds, bone pain, injections and others became the basis for gathering new disease-related information, which then becomes the raw material for reworking individual self-conceptions. Clinics, hospitals and other opportunities for interaction with peers offer the locales for gathering information on what is happening.

The disease experience enables children to assimilate information by relating what they see and hear with what they feel and think. These children do not ask about things that are not happening to them. Thus, the role of experience is largely limited to socializing children to their illness and coming to terms with the implications is of central importance. Experience also explains why age and intellectual ability are not related to the speed or completeness with which individual children pass through the various stages of awareness. Some three- and four-year-olds of average intelligence exhibit greater knowledge about their prognosis than very intelligent nine-year-olds who are still in first remission, have had fewer clinical experiences, or are only aware that they have a serious illness.

According to Schoenburg (1974), Bluebond-Langor also notes that the time lapse between stages tends to be the same for all children regardless of age. Passage from Stage One to Stage two occurs rapidly upon relapse. Passage through Stages Two, Three and Four takes somewhat longer but passage to Stage Five may take place in a few words as a child learns of the death of another, and all knowledge accumulated from the experiences of previous stages is quickly synthesized within a new self-awareness.

Analysis

Perhaps the most devastating theme in the entire literature on death and dying is the open awareness dilemma for dying children noted by Easson (1970) and Bluebond-Langor (1978) among others. Although the above evidence clearly suggests that dying children are aware of their terminal condition, acknowledgement of that awareness can bring with it social ostracism and emotional abandonment – as parents, caregivers and significant others find unbearable the added emotional burdens of the child's awareness of his/her own impending death.

Bluebond-Langor observed children seeing their own task in life as supporting others. By practicing mutual pretense these children seek to keep the parent/child and doctor/patient relationships from breaking down. They show responsiveness to the pattern of social order and to personal needs and requirements of other individuals with whom they are in contact and thereby gain in social worth what they would otherwise be deprived of by death. It allows them to act as if they have a future; to act like children. By reinforcing adults' hopes they seek to guarantee their continued presence. They allow their caregivers to practice reciprocal roles. Parents are responsible for nurturing, protecting and rearing their children. These three tasks define a parent and yet they become impossible in the face of terminal illness, forcing parents into their own forms of pretense. Through mutual pretense, physicians also may seek to salvage their self-esteem in the face of the professional failure which the death of a child represents.

Zeligs notes that when the child senses that parents and doctors are lying to him/her they lose confidence and trust in them. Karon and Vernick added that if physicians seek to protect children from realistic knowledge of their disease, this tends to result in progressive emotional devolvement of staff from the child in terminal phase almost as if s/he were already a corpse. Zeligs believes that it is the journey and not the moment of death which is so frightening to the child, who may die a thousand deaths when s/he has to cope with a conspiracy of silence. If physician and family have established a relationship of trust and confidence, the child can draw emotional support through it in his/her last days.

Numerous researchers have noted the marked tendency toward partially closed awareness and mutual pretense among dying children. Presumably, this tendency would be directly related to the social development of the child, with older children far more likely to engage in this practice than younger ones.

Conclusions

Research studies conducted among dying children strongly suggest a pattern of relationships between the growth and development of the child, the level of awareness of his/her own dying, and the child's emotional and social handling of the reality of death. Since a growing number of social workers deal with this problem regularly, further investigation of the practice implications of the research findings noted above is needed.

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