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Understanding death with limited experience in life: dying children's and adolescents' understanding of their own terminal illness and death

Alan T. Bates[a] and **Julia A. Kearney**[b]

[a]Department of Psychiatry, University of British Columbia, Vancouver, British Columbia, Canada

[b]Department of Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center, New York, New York, USA

Abstract

Purpose of review—An up-to-date summary of the literature on children's and adolescents' understanding of their own terminal illness and death.

Recent findings—Clinicians still find it difficult to speak with pediatric patients about death even though guidelines for facilitating communication on the topic exist. As a result, pediatric patients are less likely to develop a clear understanding of their illness and there is a disconnect between clinicians and parents about prognosis, even when clinicians have concluded there is no longer possibility for cure. Insufficient communication and poor understanding may increase the risk of patients feeling isolated, mistrustful and anxious, and deprive them of a role model who can communicate about painful issues or share difficult feelings. Despite these complexities, young people often show remarkable resiliency in the face of death and want to get the most out of the remaining time they have.

Summary—In addition to these most recent findings, this review examines the challenges in researching this topic, obstacles to patients receiving information about prognosis, and how physical symptoms affect patients' ability to develop an understanding. It also reviews sources of insight into pediatric patients' understanding including the development of concepts of death, fears about their own death, legal interpretations of what patients understand, and how terminally ill young people continue to treasure life. It concludes by addressing ways clinicians can use the knowledge we have to communicate well with dying children and adolescents and their families.

Keywords

death; pediatric; terminal illness

Correspondence to Dr Alan T. Bates, Department of Psychiatry, St. Paul's Hospital, 1081 Burrard Street, Vancouver, British Columbia V6Z 1Y6, Canada. Tel: +1 604 877 6000 x672488; batesubc@gmail.com.

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INTRODUCTION

Although an inescapable part of life, death is not a prominent theme in most people's day-to-day life. Most adults faced with their own mortality at the end of life grapple with difficult existential and practical questions they have not negotiated before. If this is the case for adults, then what must the prospect of looming death be like for a child? And how can we help them with the difficult uncertainties they must face? This review aims to outline what we know about children's and adolescents' understanding of their own terminal illness and provide direction for clinicians tasked with minimizing their distress.

BARRIERS TO RESEARCH EFFORTS

Recent progress in our knowledge of children's and adolescents' understanding of their own terminal illness has been relatively slow, with a number of key works published decades ago (e.g., Nagy, 1948 [1], Bluebond-Langner, 1978 [2], Sourkes, 1995[3]). End-of-life is generally an emotionally difficult time for the ill child, his/her parents, and also healthcare providers who may feel guilty about not being able to provide cure. Research suggests many healthcare providers lack experience and confidence in clinical end-of-life discussions [4], let alone negotiating patient participation in research. Some recent information has been obtained retrospectively from parents, after the patient had died (e.g., Bell et al. [5]). Direct information from children has often been interpreted from art or play through qualitative methods, making comparison across studies difficult [6]. Finally, understanding one's own terminal illness is a longitudinal and sometimes fluctuating process that may not be well captured in cross-sectional studies [6]. It is a very difficult area of research in which pioneering studies have provided valuable insights, but in which a number of questions remain unanswered.

UNDERSTANDING DEATH OF ANOTHER

Children's more general understanding of death can be broken down into four primary concepts: universality (all living things die), irreversibility (once dead, dead forever), nonfunctionality (all functions of the body stop), and causality (what causes death) [6]. Infants and toddlers are generally not able to differentiate death from separation from caregivers [7]. Partial understanding of universality, irreversibility, and nonfunctionality usually develops between the ages of 5 and 7 years, but a more complete understanding of death concepts, including causality, is not generally seen until around age 10 [6,8]. Prior to understanding nonfunctionality, children may have concrete questions such as how a dead person is going to breathe underground. Less frequently studied is the concept of personal mortality, which most children have some understanding of by age 6 [9] with more complete understanding around age 8 – 11 [10,11]. There is variability in understanding within a given age, and developmental stage (e.g., Piaget's stages) and intelligence can be other valuable indicators [6].

Understanding of causality follows an interesting pattern wherein, when asked about the causes of death, 5 – 6-year-olds most often cite nonnatural causes (e.g., violence), 8 – 9-year-olds most often cite natural causes (e.g., illness), and 11 – 12-year-olds most often cite spiritual causes (e.g., it being one's time) [6]. The reframing of causes into spiritual explanations, though less biological, is actually a more adult-like phenomenon [12] and may reflect adolescents' and adults' greater anxiety about death and religion's potential to reduce that anxiety, possibly by altering perception of irreversibility [11]. Of course, the effects of religion vary from one religion to another, and culture, political climate, and popular media can also influence how death concepts develop [11]. Reflecting underdeveloped understanding of nonfunctionality, Atwood [10] found that a quarter of 5 – 6-year-old children believed dead people could feel emotion and hunger. Children tend to understand the nonfunctionality of physical abilities (e.g., walking) before the nonfunctionality of more cognitive or emotional abilities [6], which might result in a younger child wondering what it would feel like to be dead. There are mixed findings on the effects of having a close family member die, but having potentially fatal illness does appear to advance understanding in some ways. For example, Jay et al. [13] found that children with cancer are less likely than healthy children to view death as some kind of justice or punishment.

INFORMATION RECEIVED AND TIME TO UNDERSTAND

Information about prognosis is often filtered in transfer from physician to parent to child, and each step may include delays. Wolfe et al. [14] interviewed 103 parents of children who died from cancer as well as the children's primary oncologists. Although, on average, physicians recognized there was no chance for cure 206 days before death, parents did not have the same understanding until a mean of 106 days before death. Families want to receive information about prognosis [15] and earlier recognition of grave prognosis by doctors and parents is associated with earlier discussion about hospice, and better home care [14]. However, deciding that there is no longer chance for cure can be a very difficult call even for highly experienced medical staff [16]. Also, even if prognosis has been communicated to parents, the information is not always passed on to the ill child, particularly if parents disagree with the physician's opinion. Rosenberg et al. [17*] found that concordance in opinion about prognosis between parents of children with advanced cancer and healthcare providers was poor, with parents being more optimistic and more likely to believe that cure is likely. When information about prognosis is received, some children have a lot of time to negotiate their understanding of it, whereas others have very little. Most children with cystic fibrosis now have decades to come to an understanding of what their terminal illness means to them, whereas a child with cancer might only have hours or days until death. Bell et al. [5] reported that half of initial end-of-life discussions with adolescents who died from cancer began with patients within their last month of life. Another study of children, mostly with cancer, who died in hospital describes do-not-resuscitate orders being addressed for the first time on the last day of life in 58% of cases [18].

When young patients are not informed of their prognosis, it not only gives them less time to process it and adapt, but also denies them the opportunity to observe adults modeling how to cope [19,20]. It also robs them of the opportunity to share fears and seek comfort, to have authentic though painful conversations with family and friends. It may even mean that they do not get to say goodbye to those who are important to them or to develop a sense of continuity. Children's language to discuss or think about death may be limited to cultural references or other second-hand information taken out of context and parents may be able to provide vocabulary and correct important concepts. Adolescents in particular feel it is their right to know what their prognosis is [21], and even younger children often know or suspect more about their prognosis than what they have been told [2,19]. Emotional modeling by other children with the same illness can betray parents' silence [2,19] and hospital staff also give unintentional clues [2,19]. Children may hide their knowledge to maintain membership in the support network that is ostensibly hanging on for a cure [19] or to protect their parents from direct confrontation with emotionally painful subjects. Although some children do not want to know the details of their prognosis [22], not offering to communicate with them about it generally leads to increased distress and less opportunity for authentic shared experience, grieving, comforting, and acceptance.

PHYSICAL, COGNITIVE, AND PSYCHIATRIC SYMPTOMS

The individual child's dying process and how it is managed by caregivers are likely to influence how much a child is able to deepen their understanding of dying, even when a poor prognosis has already been disclosed. For example, if the primary focus of the patient, family, and care team throughout the dying process is to reduce pain, it may leave little opportunity to address more existential concerns. Also, thoughts and feelings about dying are altered under the influence of distressing physical symptoms. Wolfe et al. [23] found that 89% of children who died from cancer suffered 'a lot' or 'a great deal' from at least one physical symptom in the last month of life, according to a retrospective parental report. Treatment for pain and dyspnea was only successful in 27% and 16% of cases, respectively. Clinically, in the face of severe pain, patients may state they do not care if they die or even express active suicidal ideation. Alternatively, pain may accentuate fear of death and sadness.

Pediatric delirium occurs in approximately 20 – 30% of patients in critical care settings [24 – 26]. Delirious patients, with fluctuating awareness and orientation, may have difficulty maintaining meaningful conversation in the last hours or days of life. In Bell et al.'s [5] sample of adolescents who died from cancer, almost 40% were using an anxiolytic medication, suggesting anxiety is another major factor. Older adolescents were particularly likely to be using anxiolytics, which might reflect their greater understanding, and thus greater existential distress. Theunissen et al. [27] surveyed parents after their child's cancer death and found sadness was the most common psychological symptom experienced by dying children and described more psychological symptoms in children older than 12 compared with those younger than 7. Healthcare staff addressed 82% of physical symptoms compared with only 43% of psychological symptoms. Furthermore, only 56% of parents' psychological symptoms were addressed, possibly leaving them ill-equipped to support their children and more at risk for psychological complications of bereavement. Underlining the degree of psychological distress are the elevated rates of posttraumatic stress disorder and subsyndromal symptoms in children and adolescents who face life-threatening illness and survive [28].

INFERRING UNDERSTANDING FROM FEARS

Expressed fears near end of life also reflect an individual child’s partial and developing understanding of death. Theunissen et al. [27] reported dying children fear being alone, physical problems, and medical treatment, which may reflect knowledge that others will not be dying with them, or that it may be a painful or uncomfortable experience. Fear of being replaced [7] may reflect understanding of irreversibility and that new life will be created after their death. Some children worry parents will not be able to recover emotionally, reflecting an understanding of others’ persisting emotional functionality despite cessation of their own. Children’s fears of being separated from familiar objects such as their clothes [11] may reflect a developing understanding of nonfunctionality wherein they understand they would not be using their things, but believe they will miss having them. Related to the various personifications of death in popular culture, children may fear monsters, ghosts, or other evil or punishing figures [11] who might serve to fill uncertainty with something more imaginable. Rather than accentuating them, talking with children about common fears is likely to reduce distress [7].

LAWS REFLECT CHILDREN’S AND ADOLESCENTS’ UNDERSTANDING

The concept of a ‘mature minor’ is now quite prevalent with differences between regions remaining and laws still evolving. In Canada, the Supreme Court ruled that ‘young people under 16 will have the right to demonstrate mature medical decisional capacity’ [29], giving children younger than 16 the right to make even life and death decisions if they are deemed to have capacity to do so. The growing legal consensus is that at least some young adolescents have the ability to appropriately weigh variables in relation to life and death decisions. A study comparing 9, 14, 18, and 21-year olds found no difference between 14-year olds and adults in their capacity to make informed healthcare decisions and noted that even 9-year olds could participate meaningfully in such decisions [30]. In Belgium, where there is no lower age limit for euthanasia (but where parental consent is required), Pousset et al. [21] have also reported evidence of adolescents being able to weigh variables related to decisions about assisted death.

DESIRE TO CONTINUE LIVING

Young terminally ill patients may become increasingly aware of still being alive, wanting to live life to the fullest. This should not be mistaken for lack of understanding of their illness. A parent interviewed in an examination of how families are supported in hospice was surprised to find that ‘children were there to live, to have the best time possible’ [31]. The same study found that young people with terminal illness want to go out and meet other children who are not ill. Adolescents with terminal illness are interested in and have concerns about sex, which may be accentuated by things that alter body image like ports and tubes. Loss of or potential for loss of sexual function and/or fertility may be a primary concern [7]. Patients’ desire to continue on with things that are important to them may coexist with feelings that they are losing their role or even their worth in life [19]. Adults’ praise of children often surrounds what they are achieving, how they are growing, and how bright their future could be. Patients may feel that, if there is nothing they will become, they have lost their primary role or worth [19]. This may contribute to depression or manifest as efforts to maintain the role of the child who is still able to impress his or her parents and make them feel optimistic about the future.

HOW TO OPTIMIZE COMMUNICATION

Children and adolescents want to receive information about their illness and treatment, and lack of communication only leads to increased anxiety, mistrust, and isolation [19,32]. Although this may seem elementary, it was not long ago that young people were routinely kept in the dark about their terminal diagnosis [33]. Death is best discussed in honest, concrete, and unambiguous terms [34]. An important part of the communication is achieved simply by being present, listening, and asking open-ended questions to assess what children already know or believe [35]. Any conversation that includes children should be held at their developmental level, with adult conversations held separately if needed. In very young patients, some communication might be through play or drawing rather than through speech [32]. Clinicians and parents should arrive at a shared understanding of what level and type of information is appropriate for each child and the appropriate level should not be chosen simply by age [22]. Out of a wish to protect their child from further distress, parents may be opposed to disclosure of upsetting information. Their feelings should be normalized, but clinicians should encourage supported, developmentally appropriate disclosure to help prepare patients for what is to come and to maintain the role of trusted adults who give reliable information. An incremental approach with intensive family support and modeling of open communication can often overcome this common barrier to inclusion of children in clinical decisions, even at end of life.

Despite their desire for autonomy, children and even adolescents generally want their parents to be involved in important decisions [21,36**]. Especially with younger children, parents commonly want to communicate information to their child themselves [32], sometimes with a clinician present to help facilitate and support them. It is important to consider cultural and religious factors, as well as history of loss, as one approach will not be appropriate for all [7]. A family’s spiritual beliefs may provide a framework for hope. Colleagues should also support each other, as end-of-life care and communication are challenging even for seasoned experts.

Frameworks, guidelines, and other tools for communication with children and adolescents around end-of-life have been developed [37]. Communication skills training, including practice-based learning through role play, has been shown to help clinicians learn skills for challenging situations such as breaking bad news, discussing prognosis, or asking about autopsy [38,39]. Not all trainees in pediatric oncology are likely to have routine opportunity to participate in such training [40], but it can be sought individually if not yet part of a particular curriculum. A version of the Five Wishes advanced care planning document tailored to young patients, Voicing My Choices [41*], was well tolerated and patients recommended it be used earlier than end of life. Another family-based intervention with adolescents with cancer has shown feasibility and efficacy in reducing distress, improving communication around adolescents’ end-of-life wishes, and reducing unnecessary disease-directed care in a patient’s last weeks of life [36**]. For younger patients, family-based or group-based interventions (e.g., the Shop Talk game [42]) may be helpful for starting difficult conversation in a nonthreatening way. Communication about death is a longitudinal process that should start early and be renewed with each significant development in the illness and as the child matures [43]. The concept of uncertainty in prognosis can be used not only to frame the discussion in reality but also to preserve hope [44**]. Some information will likely have to be relayed more than once. Young people with terminal illness appreciate clinicians leaving the door open to continued discussion.

CONCLUSION

Children's and adolescents' ideas about death develop in the context of their body experience of the illness, their shared experience with parents and other caregivers and the rest of the world around them. Although the possibility of a premature death is a difficult topic for communication in clinical and research settings, consensus is growing that young people tolerate and usually welcome opportunities to explore their own and their trusted caregiver's thoughts about life and death issues. These conversations should be supported and facilitated by clinicians throughout the illness.

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* of special interest

** of outstanding interest

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KEY POINTS

- Children's understanding of concepts of death develops over several years with partial understanding of universality, irreversibility, and nonfunctionality around ages 5–7, and a more adult-like understanding emerging around ages 10 –12 years.
- Terminally ill children and adolescents usually want to receive information about their illness and prognosis and providing them with information in a supported, developmentally appropriate way generally reduces anxiety and the sense of isolation.
- Terminally ill adolescents generally want to live whatever life they have left to the fullest and experience things that healthy adolescents do like making new friendships and exploring their sexuality.
- Communication with terminally ill children and adolescents should be tailored to them and their family, but there are structured approaches to revealing bad news that can be adapted to most situations and may help clinicians feel less anxious about having these difficult conversations.
- Although lack of experience or an urge to protect might seem like good reasons for avoiding open, clear communication, the consequences to the child (e.g., isolation, having to pretend to believe in a good prognosis, inability to share real fears or say goodbye) outweigh such concerns.