Features

Children's Views on Death and Dying: An Overview and Ethical Focus on Advance Care Planning Communication with Children

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ABSTRACT

Advance care planning is not only for adults who are dying. It is for children as well, especially children with a life-threatening or life-limiting illness. In a pluralistic society, we should also question the ethical implications of communicating with children about death. Communicating about death and advance care planning with children should vary with their age and cognitive and developmental level.

In this article, the concepts of death and cognitive development and emotional responses around death, childhood communication, and coping strategies are used to explore an approach to open communication about advance care planning that involves children, when practically possible and ethically permissible.

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INTRODUCTION

Children and death: this association may bring a shudder to some. Children are not supposed to die and they are not supposed to be exposed to death. Why? Death is taboo. But death is universal and important. As Morley D. Glicken states, "The way in which we approach and cope with death greatly influences our approach to life. It is often out of our deep fear and denial of death that we begin to deal, existentially, with the meaning of life."[1]

As rates of mortality in infants and children decline, their exposure to death may become more limited. Yet children still learn about death as part of their development, understanding the "life cycle" through everyday experiences. Without intimate exposure to death, children may become desensitized. For children who intimately face death, it is imperative to communicate clearly about death in a way that is developmentally appropriate. This article investigates children's developmental understanding of and emotional coping with death. It applies this knowledge to inform clinicians on how to communicate with children about death and advance care planning.

CONCEPTS OF DEATH

There are several theoretical frameworks to describe and evaluate the concepts of death and children. Examples include the psychoanalytic, intuitive, and cognitive frames. The psychoanalytic approach delves into children's concepts of death in order to explore and potentially help support their emotional responses to death.[2] This approach can be contrasted with the intuitive approach, that, as Virgina Slaughter and Maya Griffiths write, explores "children's knowledge about death in terms of their developing intuitive, or folk knowledge about the domain of biology."[3] The cognitive framework, specifically that proposed by Jean Piaget, correlates changes in a child's understanding of death with cognitive development (see table 1).[4]

These three approaches often do not account for the diversity in the understanding of death and children in different cultures. Maureen Callanan notes that we often fail to account for the sociocultural, religious, and conflicting beliefs that coexist in children.[5] Difficulties exist in comparing these across cultures. Some of the nuances in understanding death that include environmental and religious exposures may be easier to distinguish once children are able to have abstract thoughts. Future research may be helpful in exploring these ideas.

The three approaches generally agree that for children to have a "mature" understanding of death, they must grasp several concepts. These concepts of death progress with age and include: (1) inevitability or universality (all living things die), (2) irreversibility or finality (the dead body cannot come back to life), (3) cessation or nonfunctionality (all living functions end upon death), and (4) causality (living things die as a result of various biological reasons or bodily breakdown).[6] The concepts of unpredictability and personal mortality[7] are not universally included. These concepts usually solidify between five and 10 years, but may occur earlier in those exposed to death at an earlier age.[8]

Infants and toddlers may have difficulty differentiating death from their separation from a parent.[9]

TABLE 1. Developmental conceptualization of death

Age	Piaget's stage	Piaget's development	Concept of death
Birth-2 years	Sensorimotor	Understands world through senses and motoric manipulations; attachment bond is created.	Has difficulty distinguishing death from separation, but does experience loss, especially in inconsistent environments.
2-3 years	Pre-operational	Uses symbolic reasoning and magical thought; illogical thinking is dominated by perception; is egocentric; fears separation; believes in animism.	Struggles to understand irreversibility. Can deny death exists (dead body could be sleeping). Can believe anger (or other emotion) or an action (going to the hospital) caused death of another. Acts out feelings rather than verbalizes them.
4-6 years	Pre-operational	See above. Often concerned with death, as an attempt to develop a definition of life.	Has partial concepts of inevitability, irreversibility, and cessation. Example: a child who does not yet understand cessation has concrete questions such as "How does a dead person breathe or eat underground?" Causality is not fully formed. May cite nonnatural or violent causes of death.
6-12 years	Concrete operational	Develops logical thought to solve problems; develops distinction between animate and inanimate objects; acquires knowledge and develops peer relationships.	Death is seen as concrete and can be externally or internally caused, such as by illness. Can mention spiritual causes ("It is one's time"). Can personify death (i.e., Grim Reaper, Angel of Death, ghosts, etc.). Can make an oath on own death or parent's death. Can consider funerals to be an ill omen. Can cross fingers and say verses to ward off evil and protect self. May accept finality of death, but often applies it to others, not self.
13-19 years	Formal operations	Abstract thought, scientific reasoning form personal identity and social interests.	Death is final, universal, and becomes abstract, but can still question death.

However, by five to seven years of age, children typically have acquired partial concepts of inevitability, irreversibility, and cessation.[10] Piaget notes, "Questions of children of the ages of 5, 6 and 7 are also very often concerned with death, and show their attempts to find a definition of life. . . . The animism of younger children is much more implicit and unformulated. They do not question whether things know what they are doing, nor whether things are alive or dead, since on no point has their animism yet been shaken."[11]

By 10 years of age, the concept of causality begins to develop and matures further still with age, intelligence, and development. A pattern can be seen in children as they develop the concept of causality. Children ages five to six often cite nonnatural or violent causes of death; children eight to nine years old cite natural or illness-related causes; 11 to 12 year olds may cite spiritual causes such as it "being one's time."[12] Children who consider suicide or homicide may not be fully mature in their understanding of death and its finality.[13]

Children are savvy detectives and pay particular attention to hushed conversations, telephone calls, and "evasive" clues, especially when the topic is "off-limits" or secret.

Notably, predictors of understanding death include cognitive ability and age, but not maternal communicative competence, as proposed by some researchers.[14] Specific cognitive development of a vitalistic causal-explanatory framework assists in children's learning about life and death.[15] Additionally, there is conflicting evidence about socioeconomic status, race, ethnicity, and exposure to death in how children assimilate their understanding of death.[16] Therefore, examining cognitive development may be the most helpful in learning what children understand about death.

While Jean Piaget's theory of cognitive development "emphasizes the active role of the child in discovering and constructing reality, evolving from sensorimotor approach, through stages of concrete reasoning, to the capacity for abstraction,"[17] Erik Erikson's psychosocial approach to development "describes psychosocial 'crises' that the child must negotiate in the formation of his or her sense of self and in relation to others (trust versus mistrust, autonomy versus shame and doubt, initiative versus guilt, and industry versus inferiority)."[18] Both of these approaches posit a linear progression through development, which is similar to other paradigms, such as Elizabeth Kubler-Ross's initial proposal of the stages of grief,[19] and Lawrence Kohlberg's[20] or Carol Gilligan's[21] description of the progression of moral development. However, children may vacillate or cycle among stages. Serious illness and death can challenge the forward progression, especially if a child's emotions and/or environment radically shift.

CHILDREN'S EMOTIONS ABOUT DEATH

Children have emotional responses to death that are similar to those of adults. In addition to denial, anger, bargaining, depression, and acceptance, they can experience sadness, guilt, shame, pain, loneliness, despair, embarrassment, ambivalence, hope or hopelessness, helplessness, confusion, and peace, to name a few. One strong emotion that is intimately linked to death in adults and children is fear.

The fear of death may be innate, acquired, or a combination of the two. Gregory Zilboorg, Nelli L. Mitchell, and Karen R. Schulman, supporters of the idea that this fear is innate, believe that there is a need to fear death in order to preserve a species.[22] Similar to the stress responses of fight and flight, fear may be a response that is needed to avoid the danger of death for as long as possible. Mitchell and Schulman state that the "terror of not being"[23] begins in childhood and often persists. Mitchell and Schulman believe that this emotional response to death, especially the "dread of annihilation and mutilation," transcends the intellectualization of death.[24] However, they write, "the fear of death in children is intensified by the absence of the intellectual equipment and by the absence of necessary defensive mechanisms essential for comprehending the experience of loss."[25] Therefore, the ability to repress or mindfully embrace this fear of death may be taught by society to aid in coping with loss or death.

Others believe that the fear of death may be acquired during the process of death conceptualization and maturation. For instance, Piaget proposes that young children seem to have less fear of death than older children because they do not truly understand death. However, Piaget remarks that some children "are haunted every night by fears of death, either for themselves or their parents."[26] This may be normal temporarily or may pathologically persist.

Further still, when children have not developed a biological conceptualization of death, rather than a behavior-related conceptualization, their fear of death can be exacerbated. As Slaughter and Griffiths describe, children's "immature conceptualization of death leads them to focus on un-resolvable questions like, 'why do some people I love decide to go live under ground instead? Will he or she come back soon? Isn't it cold down there?' "[27]

Loss, separation, and death are essential concerns for individuals, including children. Having more advanced cognitive and emotional development may help in coping with these essential concerns, notably anticipatory grief in children who are facing their own death or the death of a loved one.

CHILDREN FACING THEIR OWN DEATH: FOCUS ON CHILDREN WITH CANCER

Children with relapsed, progressed, or terminal cancer generally know that they are dying.[28] They are forced to confront mortality. They know this whether or not someone tells them.[29] Studies have found that children are keenly aware of death and often know more than their parents believe they do. Children are savvy detectives and pay particular attention to hushed conversations, telephone calls, and "evasive" clues, especially when the topic is "off-limits" or secret. Often times, children do not talk about death to protect their parents and family members.[30]

Despite communication with children about death, or the lack thereof, children experience anticipatory grief or, as Barbara M. Sourkes describes it, "grief expressed in advance when the loss is perceived as inevitable."[31] Family members may not even notice a child's grief. In order to identify anticipatory grief, family members must pay close attention. Children leave many clues. They begin to make matter-of-fact statements about death, play act, or draw about death.[32] They often times have nightmares, have sleep disturbances, or act out.[33] Those who attend to a dying child may observe the signs of preparation the child makes to confront impending death. As Sourkes writes, "The dying child's anticipatory grief is palpable as he or she lives the intensity of separation in its ultimate form."[34]

In coping with separation, especially a separation as significant as death, a therapist may be helpful. One dying six-year-old child said to a therapist, "Thank you for giving me aliveness."

When a child faces imminent death, it is devastating for all involved. There is a plethora of literature that delves into the physical, psychological, and social layers of complexity in supporting children, their family members, and their healthcare providers during this difficult time. One of the first to investigate how children perceive their terminal prognoses and death was the anthropologist Myra Bluebond-Langner, who completed *The Private Worlds of Dying Children* in 1977.[35] This ground breaking work explores awareness and communication in children with leukemia, at that time a terminal diagnosis. She found that children knew of their prognosis, even when parents and healthcare providers went to extensive lengths to "protect" them from that knowledge. This book began a wave of change that facilitated more open communication with children about their diagnosis and prognosis. It opened the door to provide shared experiences and a meaningful time for children and their family members at the end of life.

Since then, studies have found that parents who talk honestly with their children about death have less regret than those who don't.[36] Children who are actively dying may experience physical, psychological, social, and spiritual pain.[37] Having an opportunity to address these woes can be beneficial and exceed the discomfort experienced by those who address them. Children fear suffering until the end of life, fear being alone at the time of death, worry about those surviving them,[38] and desire to make the most of the life they have left.[39] Open communication can provide a means to promote familial healing, including healing for well siblings who are often overlooked during a child's cancer journey.

COMMUNICATING WITH CHILDREN ABOUT DEATH

How do children communicate about death? Usually they ask questions like, "Why do people die?". This may occur after exposure to death in the media or experientially.[40] Most parents feel unprepared for such questions, and their responses vary. The best way to communicate with a child about death should be adapted to each child, parent, and situation. Parents must gauge their child's personality, temperament, and situation. While parents' words may vary, a gentle, caring, and responsive manner is better received than a cold, unsympathetic, or unresponsive one.[41] It is important to observe children's reactions during communication. They often provide their own "barometer," and will limit the amount of information they can handle. When they meet their limit, they change the subject, run away to play, or find a distraction. When they are ready to discuss death again, they will bring it to a caregiver or friend's attention.

Each child requires individualized communication, but there are some key concepts that can be helpful when discussing death. Slaughter and Griffiths write, "Researchers and clinicians have advised adults to discuss death in truthful, concrete and unambiguous terms with children."[42] This means using words such as "died," "dead," and "death," as opposed to "sleeping," "passed away," or "was lost." This communication must be developmentally appropriate, and it is appropriate to respond to a child's question with a question, such as "Why do you ask?". As Kenneth J. Doka advises, "Children of the same age are not necessarily of the same [cognitive] and emotional level of development."[43] If responses are out of proportion with a child's developmental level, the child's understanding may not be real. For instance, when children nod their head in silence and walk away, this does not verify understanding as it would in an adult; children often are attempting to have the adult leave them alone.[44] True understanding can be validated when children can explain what they were told in their own words. Sometimes, they may frame the information in terms of a familiar reference to death, such as a book like *Charlotte's Web*.[45] This childhood classic is often a favorite of dying children.

CHILDREN COPING WITH DEATH: PLAY THERAPY AND DRAWING

In coping with separation, especially a separation as significant as death, a therapist may be helpful. One dying six-year-old child said to a therapist, "Thank you for giving me aliveness."[46] Therapists and child-life specialists are trained to use play to approach children at their level. Sourkes states, "Play enables the seriously ill child to 'reenter' childhood."[47] She notes, "Shared imaginative play enables the child to confront the realities of life and death."[48] Other methods to help children cope with death include memorabilia, stuffed animals, and making legacy items.[49] Some children engage in making lists of feelings, drawing mandalas, and writing or reading books.[50]

ETHICS OF COMMUNICATING TO CHILDREN ABOUT DEATH AND DYING

Previously it was thought that withholding information from children about death would protect them, in a paternalistic form of therapeutic privilege. However, more recent research indicates that truthful disclosure in a developmentally appropriate manner is often beneficial to both children and families. Truthful disclosure may decrease children's psychological distress as they approach death and the distress of their bereaved surviving siblings.

Respect for persons is a key ethical concept to honor. For healthcare providers, it is important to ask parents, guardians, or significant family members what they prefer that the child be told, and how. Parents are more likely to allow a discussion of terminal illness or impending death with their child once they realize that the benefits of these discussions outweigh the harms. However, the benefits could be overshadowed by harms if a child is told in an inappropriate manner. It is better that parents help to determine the safest manner to communicate about an illness with their child.

The legal aspects of disclosing information to minors are not evaluated here, but cases exist that support both disclosure and nondisclosure to children. The courts often support the fiduciary duty of honesty to trusting patients. From a justice perspective, there should be adequate resources provided to children and their family members to aid in their anticipatory grief and bereavement. One way to incorporate children into the process is to help them with age-appropriate advance care planning (ACP). Involving children in ACP may thus become an ethical and professionalism consideration for caregivers and clinicians.

INVOLVING CHILDREN IN ACP

ACP involves making decisions about the care a person would like to receive when the person cannot speak for her- or himself, or when the person's autonomy and capacity are limited. ACP for children, whose development of autonomy and capacity is emerging, involves discussing their hopes, wishes, and worries, and planning ahead for their future care, including the preferences of the child and family members. Making these decisions can be challenging, but it helps to honor the child's preferences and the family's values. These values and preferences may not be known unless they are specifically discussed. The obligation to learn about these values and preferences is not legally binding in many states, but it is an ethical duty for clinicians, especially for those who care for children with life-limiting or life-threatening illness.

Other barriers that parents reported included healthcare providers' reluctance to discuss ACP due to prognostic uncertainty, or because providers were not "willing to face up to the facts," and perhaps because parents had individualized needs, concerns, and coping mechanisms.

Children have the added challenge of being minors; despite good conversations and advance care planning, their wishes may not be followed because they are not their own legal decision makers. Typically in pediatric care, parents, legal guardians, or surrogate decision makers provide permission for the care given to their child. In some cases, children may voluntarily provide assent for care; however, children do not have the power to provide consent, unless they are emancipated minors. Because children do not have the legal power or competence to provide consent or dissent to certain modalities of care, their voices may be lost in decision making, despite recommendations to involve children when appropriate[51] and possible.[52]

Before considering possible barriers to involving children in ACP, the general barriers to conducting advance care discussions for children with life-threatening conditions should be considered. Amy Durall and colleagues surveyed 266 healthcare providers and identified three main barriers to involving children in ACP: parents' unrealistic expectations, the differences between clinicians' and patients'/parents' understanding of prognosis, and parents' lack of readiness to have a discussion.[53] Durall and colleagues found significant differences in the barriers identified by nurses and physicians. Nurses more often identified ethical considerations to be barriers, and the unimportance of these ethical considerations to clinicians. Physicians said that ACP discussions are important, but not knowing what to say during theses discussions was a barrier. On the caregivers' side, potential barriers included cultural or religious beliefs, poor prognostic awareness, a fear of abandonment after a decision was made, feeling alone in making a decision, or fear of regret in making a decision.

ACP does not mean "giving up" on a patient, but rather aligning the medical plan with the patient's and family's goals of care. Because the goals of care can shift over time as an illness evolves, as the side-effects of a treatment change, or when certain experiences with a treatment occur, ACP may need to be readdressed. Therefore, it is important for careproviders to communicate clearly that the patient and family members will not be abandoned, and will be supported in the decision-making process.[54]

Parents may have mixed feelings about ACP. Julia Lotz and colleagues conducted in-depth interviews with bereaved parents and found, on the one hand, that some parents reported that ACP helped them to be good parents, facilitated coping, and empowered them to make decisions for their child.[55] Parents believed ACP gave them a sense of control and security by preparing them for what was to come. On the other hand, some parents identified personal barriers of not feeling ready, wanting to focus on the present, or attempting to suppress burdensome thoughts. Other barriers that parents reported included healthcare providers' reluctance to discuss ACP due to prognostic uncertainty,[56] or because providers were not "willing to face up to the facts," and perhaps because parents had individualized needs, concerns, and coping mechanisms. Parents expressed a desire for ACP to involve shared decision making and a communication strategy that is gradual, sensitive, maintains hope, and involves children relative to their developmental maturity—which did not include infants. Specifically, parents "felt that their child should be heard and taken seriously even if unable to make treatment decisions."[57]

Potential barriers included parents' cultural or religious beliefs, or their concerns that their child did not have the cognitive capacity to understand, or the emotional capacity to participate. Another barrier was providers' or caregivers' not knowing what to say or how to answer a child's questions. Some caregivers might desire to have their child participate in ACP discussions, but that the first of these discussions not be with a healthcare provider. Giving caregivers time to discuss ACP with healthcare providers without a child present may help the caregivers process emotionally, freely obtain information, ask difficult questions, and develop an understanding without worrying about the child's response to the information. Some parents may prefer that a family member or a member of the healthcare team, other than the child's physician, discuss ACP with the child. For instance, a child may have a closer relationship with a child-life specialist and prefer to speak with that person.

Inviting a child to participate in ACP can be time consuming. A child may need to take breaks from the discussion, and ACP may need to occur over a series of conversations. Starting the conversations earlier in a child's illness may facilitate the gathering of information and give the child and family the space they need to formulate their thoughts. Because ACP takes into account the wishes, hopes, worries, and preferences of the child and family, the "plan" will be individually nuanced. ACP for children needs to be flexible, as patients and parents may change their minds on what they desire over time.[58]

Despite all of these barriers, knowing the wishes of children at the end of life is helpful. Healthcare providers have a fiduciary duty to protect the welfare of children, especially at the end of life. [59] By involving the preferences of children in ACP, not only are caregivers informed of what the children desire, but the possibility that their preferences are honored increases. When children's preferences are honored, their quality of life improves and family members have improved bereavement outcomes.[60]

There is little research around the involvement of young children in decision making, but guidelines of care continue to support patient- and family-centered or shared decision making. More research has been done with the involvement of adolescents and young adults (AYA) in ACP. By and large, research indicates that AYA want and are able to choose and record (1) the medical treatment they do and do not want, (2) how they would like to be cared for, (3) the information they want their friends and family members to know, and (4) how they would like to be remembered.[61] Some AYA who are undergoing hematopoietic stem cell transplant indicate that they want to continue many medical interventions at the end of life rather than limit them, which may demonstrate the conflict of balancing cure and comfort.[62] Like any patient at the end of life, AYA may change their mind. Jennifer Mack and colleagues found that AYA with recurrent or stage IV cancer initially favored life-prolonging interventions, but later preferred for comfort care.[63] Maureen Lyon and colleagues report on a randomized controlled trial with pediatric oncology patients; they found that the patients and families who completed an ACP program consisting of a survey, a Respecting Choices interview, and the *Five Wishes* program, were more likely to agree to limit treatment at the end of life than a control group who received standard care.[64] Similar results were found with AYA who had HIV/AIDS.[65] Adolescence is a time when separation from patents is normal, and teens are forming a better sense of self, as so AYA may mimic the values and preferences of their parents—or they may not. A transition of preferences and values does not necessarily need to cause familial discord. With open communication, families may come to understand the perspective of AYA, and vice versa.

COMMUNICATING WITH CHILDREN AND FAMILIES ABOUT ACP

Communication with patients and family members is the most important tool in establishing therapeutic relationships. If communication is stilted, impaired, misconstrued, or abused, the therapeutic relationship may be lost, and prevent any healing possibility. While communication is essential in all clinical encounters, it is of the utmost importance to be caring, compassionate, and clear when discussing ACP and end-of-life care (see table 2).

Respect for the values of patients and family members is essential to support a therapeutic relationship. This respect involves understanding the preferences of patients and families and aligning care with those preferences, as medically feasible and practically possible.[66] Coercion or an attempt to bias decisions per a healthcare provider's values is not ethically permissible. Inviting children into the discussion may be ethically permissible and is promoted professionally in the field of pediatrics. As the American Academy of Pediatrics states, "The child should participate to the fullest extent possible, given his or her preferences, cultural and spiritual tradition, illness experience, developmental capacity, and level of consciousness."[67]

How does one learn of these wishes or involve children, adolescents, and young adults in ACP? Building on the foundation of excellent communication, helpful guides to ACP for children include *My Wishes* and *Voicing My Choices,*[68] which are similar to the *Five Wishes* ACP guide. These ACP booklets avoid the legal jargon often seen in adult forms. Other interactive modalities include card and board games, such as "Go Wish"[69] and "Shop Talk,"[70] respectively. Another modality to communicate with children about ACP may include an interactive technology called "The Compass."[71] This tool, that is under development, uses technology similar to computer or video games to illicit a child's ideas, goals, priorities, and desires related to end-of life-care.[72] Teaching healthcare providers excellent communication skills and to utilize their support staff and resources may promote including children in ACP.

CONCLUSION

Cognitive and emotional responses to death can be striking, but children of all ages can be well supported in a developmentally appropriate manner. Discussing death may be uncomfortable, but if it is done in an honest, gentle, and caring manner, outcomes are improved. This includes communicating to dying children that they will not be alone. Alleviating fears, making memories, and giving children some control will help them to experience some comfort despite their distress. Leaving a legacy is important to children. For survivors, especially child survivors, open communication may facilitate resilience and decrease maladaptive responses, ranging from disturbed sleep to acting out. Involving children in ACP may not only improve goal-concordant care, but may bring solace to surviving family members. Utilizing this framework, talking about death can become less taboo, scary, and difficult, and instead become an opportunity for providers, families, and children to work together to give each child the best care possible.

NOTES

1. M.D. Glicken, "The Child's View of Death," *Journal of Marriage and Family Counseling* 4 (1978): 75.

2. V. Slaughter and M. Griffiths, "Death Understanding and Fear of Death in Young Children," *Clinical Child Psychology and Psychiatry* 12 (2007): 525-35, 526.

3. Ibid.

4. Briefly, Jean Piaget's theory delineates four linear stages of cognitive development that progress from the sensorimotor stage (typically birth to two years of age), the pre-operational stage (two to seven years of age), the concrete operational stage (seven to 12 years of age) and the formal operational stage (adolescence to adulthood). In the sensorimotor stage, children "understand their world through their senses and motoric manipulations." S.B. Hunter and D.E. Smith, "Predictors of Children's Understandings of Death: Age, Cognitive Ability, Death Experience and Maternal Communicative Competence," *Omega* 57 (2008): 145.

During the pre-operational stage, children use symbolic reasoning and magical thought in approaching the world; "their thinking at this stage is illogical because it is dominated by perception." Hunter and Smith, "Predictors," 145. They are often egocentric, have a fear of separation, participate in magical thinking, and believe in animism. *Animism* is the attribution of nonliving things having life or of living things, such as plants, having souls. Animism is similar to personification. Children older than 12 years see life as a property of animals and plants, but can distinguish animate and inanimate objects. In approaching something that is alive, children in this stage may see it as "functional, active or undamaged." Glicken, "The Child's View," see note 1 above, p. 75.

Those in the operational stage struggle to understand irreversibility and deny that death exists. A dead body may seem to be sleeping to them. They may also believe that their anger caused the death of another. In the operational stage, logical thought is used to solve concrete problems. Thus, death is concrete and can be externally or internally caused. The personification of death is realized. An example of this personification would be the "Grim Reaper," the "Angel of Death," or ghosts. In this stage, children may accept the finality of death, but more often they will apply it to others than to themselves.

Finally, in the formal operations stage, abstract thought and scientific reasoning arises. At this stage, death is final, universal, and becomes abstract. While a child is continuing to mature in this stage, the finality of death

TABLE 2. Communication for children with a serious illness who are approaching death

Age	Needs to be met	Anticipation	Coping and communication strategies	Advance care planning
Infants	Provide a secure, consistent, loving presence and comfortable surroundings.	Will not anticipate death, but may sense the anticipation of family members.	Encourage families to celebrate milestones and make memories. Provide families with requested information. Ensure social and emotional supports are available to families.	While infants will not be involved in ACP, parents, siblings, and family systems have particular needs with the loss of an infant.
Preschool	Provide a safe, loving environment. Help child interpret feelings expressed through actions. Provide realistic choices for child.	May anticipate death, especially if the child knows other children in a similar situation who died after doing a particular action (like going to the hospital or taking a medicine).	Encourage families to continue normal rituals as possible, celebrate milestones, and make memories. Storytelling and creating stories with children may help careproviders learn about a child's worries and hopes.	Invite the child to "tell his or her story" in a way that may aid in developing ACP.
School age	Provide a safe, loving environment and a listening ear. Provide realistic choices for the child. Roles and goals may provide purpose.	Will anticipate death and may have significant fear of separation. May ask details about death and dying. May focus on how unfair it is to be going through this. Will worry about how death will impact other family members.	Provide honest, straightforward explanations to questions; provide illustrations and demonstrations to facilitate communication. Child may desire to plan a funeral, write a will, or plan for special items (like a teddy) or family roles. Ensure connection with peers if desired. Celebrate milestones and make memories. Reassure child that pain will be treated. Let child share personal story with others. Listen to child.	Involving a child in ACP at this age is critical as it can empower the child. Play acting, drawing, or walking through a communication tool may be helpful. Consider the use of the "My Wishes" tool.
Preteen	Provide a safe, loving environment. Roles and goals may provide purpose.	Child will anticipate death, but at times may be emotionally labile, ambivalent, or focused. Expressions and actions may be inconsistent. Will express injustice regarding dying or death.	Honestly answer questions and address child's concerns. Distraction may help at times. Celebrating milestones, making memories, and especially making meaning from experiences will be important. Ensure that the patient is connected with peers, if desired.	Involving child in ACP at this age is critical, as it can empower the child. Asking open-ended questions or using a communication tool may be helpful.
Adolescents	Provide a safe, loving environment. Learn about short-term and long-term goals. Child may need help to balance hopes for the future and to find meaning in the present circumstances. Child will need others to know what is important to her or him.	While teen may be vulnerable while anticipating death, he or she may still make impulsive decisions when feeling invulnerable. Teen may worry that people will forget about him or her after teen dies.	Honestly answer questions and address concerns. Celebrate milestones, make memories, make meaning from experiences, and develop a legacy. Ensure teen has connection with peers and avoids isolation. Help teen maintain activities. Image may be a major focus for teens. Provide support around body image concerns.	Promote open communication with the healthcare team. Ask open-ended questions, listen to preferences and provide choices. Ensure ACP involves the teen. Consider using "Voicing My Choices" booklet.

can still be questioned. However, "the ability of the child at age ten to discuss death often signifies his emancipation from childhood. Children take oaths on their own death or parent's death. Funerals are considered ill omens and children cross fingers and say verses to ward off evil and protect themselves." Glicken, "The Child's View," see note 1 above, p. 76.

5. M.A. Callanan, "Diversity in Children's Understanding of Death," *Monographs of the Society for Research in Child Development* 79 (2014): 142-50.

6. A.B. Sood et al., "Children's Reactions to Parental and Sibling Death," *Current Psychiatry Reports* 8 (2006): 115-7; M. Cuddy-Casey and H. Orvaschel, "Children's Understanding of Death in Relation to Child Suicidality and Homicidality," *Clinical Psychology Review* 17 (1997): 33-45; Slaughter and Griffiths, "Death Understanding," see note 2 above; A.T. Bates and J.A. Kearney, "Understanding death with limited experience in life: Dying children's and adolescents' understanding of their own terminal illness and death," *Current Opinion in Supportive and Palliative Care* 9 (2015): 2; Hunter and Smith, "Predictors of Children's Understandings," see note 4 above, 143-4.

7. Personal mortality is often realized initially around six years of age, but develops more between the ages of eight to 11.

8. Slaughter and Griffiths, "Death Understanding," see note 2 above, p. 526; Sood et al., "Children's Reactions," see note 6 above, p. 115; Cuddy-Casey and Orvaschel, "Child Suicidality and Homicidality," see note 6 above, pp. 40-1.

9. Children in the sensorimotor stage do not have the cognitive and expressive skills for adults to investigate and classify as clearly as those of older children.

10. A child who has not yet understood cessation might ask a concrete questions such as, "How does a dead person breathe or eat underground?".

11. J. Piaget, *The Child's Conception of the World* (London, U.K.: Routledge and Kegan Paul, 1929), 210.

12. Bates and Kearney, "Understanding Death," see note 6 above, pp. 2-3.

13. Cuddy-Casey and Orvaschel, "Child Suicidality and Homicidality," see note 6 above, p. 42.

14. Hunter and Smith, "Predictors of Children's Understandings," see note 4 above, pp. 143-62.

15. V. Slaughter and M. Lyons, "Learning about life and death in early childhood," *Cognitive Psychology* 46 (2003): 1-30.

16. M. Tallmer et al., "Factors Influencing Children's Concepts of Death," *Journal of Clinical Child Psychology* 3 (1974): 17-9.

17. B.M. Sourkes, *Armfuls of Time: The Psyhological Experience of the Child with a Life-Threatening Illness* (Pittsburgh, Penn.: University of Pittsburgh Press, 1995), 8.

18. Ibid., 8-9.

19. Per Kubler-Ross, the stages of grief include the following: denial, anger, bargaining, depression, and acceptance. E. Kubler-Ross, *On Death and Dying* (New York, N.Y.: Macmillan, 1969).

20. The stages of moral development delineated by Lawrence Kohlberg focus on justice and include the following: (1) pre-conventional level, stage 1—obedience and punishment; (2) pre-conventional level, stage 2—individualism, instrumentalism, and exchange; (3) conventional level, stage 3—"good boy/girl"; (4) conventional level, stage 4—law and order; (5) post-conventional, stage 5—social contract; and (6) post-conventional level, stage 6—principled conscience. School-age children usually achieve the first level, whereas the general public achieves the second level, and only a minority of adults achieve the third level. There is a steady progression without jumping past the different stages. L. Kohlberg, "The development of children's orientations toward a moral order. I. Sequence in the development of moral thought," *Vita Humana Internationale Zeitschrift für Lebensaltersforschung* 6 (1963): 11-33; R.N. Barger, "A Summary of Lawrence Kohlberg's Stages of Moral Development," University of Notre Dame, 2000, *https://www.csudh.edu/dearhabermas/kohlberg01bk.htm.*

21. Carol Gilligan argued that Kohlberg's classification favors males. From a feminist and, some would say, ethics of care approach, Gilligan developed a schema for moral development that also has a progression through stages. She later states that she views moral development through histories or cultural framework rather than in stages, but the focus is the idea of linear developmental progression. The stages Gilligan delineates include: (1) preconventional with a goal for survival, and transition from selfishness to responsibility to others; (2) conventional with a goal of self-sacrifice and transition from goodness to truth that the other person is a person too; (3) postconventional with a goal to not hurt others or self (principle of nonviolence). C. Gilligan, "New Maps of Development: New Visions of Maturity," *American Journal of Orthopsychiatry* 52 (1982): 199-212; G. Jorgensen, "Kohlberg and Gilligan: Duet or duel?" *Journal of Moral Education* 35 (2006): 179-96.

22. G. Zilboorg, "Fear of Death," *Psychoanalytic Quarterly* 12 (1943): 467; N.L. Mitchell and K.R. Schulman, "The Child and the Fear of Death," *Journal of the National Medical Association* 73 (1981): 963-7.

23. Mitchell and Schulman, "Child and Fear," see note 22 above, p. 963.

24. Ibid., 964.

25. Ibid.

26. Piaget, *Child's Conception,* see note 11 above, p. 136.

27. Slaughter and Griffiths, "Death Understanding," see note 2 above, p. 527.

28. There have been great gains in cancer therapy and supportive care, leading to a survival rate of 80 percent for some cancers, but cancer is still a life-threatening illness. Notably, the outcomes vary among the different types of cancer, with survival rates greater than 90 percent in some forms of acute lymphoblastic leukemia and about 70 percent for some solid tumors and brain tumors. R. Siegel et al., "Cancer Statistics," *CA: A Cancer Journal for Clinicians* 62 (2012): 10-29; E. Ward et al., "Childhood and adolescent cancer statistics, 2014," *CA: A Cancer Journal for Clinician*s 64 (2014): 83-103.

29. Parents and society may try to hide the impending death of a person, including that of the child his- or herself. For instance, Isabel T. Gutierrez et al. found among "highly educated, mostly European American parents" that "35% of the parents . . . shielded their young children from representations of death in books, but twice as many parents (75%) . . . shielded their children from representations of death in television and movies." However, in the same study, "21% of parents said that they used a book about death as a resource for helping their young children cope with death." I.T. Gutierrez et al., "Affective Dimensions of Death: Children's Books, Questions, and Understandings," *Monographs of the Society for Research in Child Development* 79 (2014): 43.

30. Callanan, "Diversity in Children's Understanding," see note 5 above, p. 145.

31. B.M. Sourkes, "The Broken Heart: Anticipatory Grief in the Child Facing Death," *Journal of Palliative Care* 12 (1996): 56.

32. Some of the play acting may resemble a battle or fight, as war imagery is often portrayed by society when it references the "fight against cancer." This idea began many years ago; for example, Kearney wrote in 1977: "a former colleague Dr. R.K. Whyte liked to quote Shakespeare when initiating cancer treatment in children, 'Cry "havoc!" and let slip the dogs of war,' clearly indicating the nature of effective treatment. It really is a war and the child is the battlefield. For the parents it must be like living through a blitz. After a time a modus Vivendi emerges, but always there are reminders of the threat." P.J. Kearney, "Ethics, Cancer and Children," *Medical Hypotheses* 3 (1977): 178.

33. Doka found at Oakland Children's Hospital that "children exhibit their feelings through sleep disorders and acting out (personal communication) . . . [they] also engage in little adult behaviors: . . . acting like the deceased, experiencing psychosomatic illnesses, fearing illness, fearing losing control, regressing, being unable to separate, refusing to mention the deceased, losing appetite or overeating, bed-wetting, and feeling depressed." K.J. Doka, *Children Mourning, Mourning Children (*Washington, D.C.: Hospice Foundation of America, 1995), 128-9.

34. Sourkes, "Broken Heart," see note 31 above, p. 58.

35. M. Bluebond-Langner, *The Private Worlds of Dying Children* (Princeton, N.J.: Princeton University Press, 1978).

36. U. Kreicbergs et al., "Talking about Death with Children Who Have Severe Malignant Disease," *New England Journal of Medicine* 351, no. 12 (2004): 1175-86.

37. C. Saunders, "The symptomatic treatment of incurable malignant disease," *Prescribers' Journal* 4, no. 4 (1964): 68-73.

38. Bates and Kearney, "Understanding Death," see note 6 above, p. 5.

39. Ibid., 5-6.

40. Gutierrez et al., "Affective Dimensions," see note 29 above, p. 50.

41. Doka, "Children Mourning," see note 33 above, p. 20; K. Palma, "Talking to young children about death," *Boston.com,* 2015, *https://www.boston.com/culture/parenting/2015/07/28/talking-to-young-children-about-death.*

42. Slaughter and Griffiths, "Death Understanding," see note 2 above, p. 534.

43. Doka, "Children Mourning," see note 33 above, p. 90.

44. Ibid., 91.

45. That *Charlotte's Web* is a favorite among children, especially dying children, is not new. Parents were asked to list children's favorite books, and 3 percent of the books (six books) depicted death. Three of these six books were winners of the Caldecott Medal: *Charlotte's Web; Fables;* and *Sam, Bangs & Moonshine.* The other three books were *The Wonderful Wizard of Oz; Hansel and Gretel;* and *The Big Book of Dinosaurs.* Gutierrez et al., "Affective Dimensions," see note 29 above, p. 45. A. Wilkes, *The Big Book of Dinosaurs* (New York, N.Y.: DK Penguin Random House, 2015); E.B. White, *Charlotte's Web* (New York, N.Y,: HarperTrophy, 2016); A. Lobel, *Fables* (New York, N.Y,: HarperTrophy, 1983): J. Grimm and W. Grimm, "Hansel and Gretel," in *The Original Folk and Fairy Tales of the Brothers Grimm: The Complete First Edition,* reprint, trans. J. Zikes (Princeton, N.J.: Princeton University Press, 2014), 43-8; E. Ness, *Sam, Bangs & Moonshine* (Markham, Ont., Canada: Fitzhenry and Whiteside, 1966); L.F. Baum, *The Wonderful Wizard of Oz* (Chicago, Ill.: George M. Hill, 1900).

Bluebond-Langner observes that *Charlotte's Web* is often requested by dying children to be read to them in their last few days. Bluebond-Langner, *The Private Worlds of Dying Children,* see note 35 above.

46. Sourkes, "The Broken Heart," see note 31 above, p. 59.

47. Sourkes, *Armfuls of Time*, see note 17 above, p. 5.

48. Ibid., 7.

49. Examples of legacy items could include ink prints of hands or feet, photos, scrapbooks, video and or audio recordings, artwork, letters to read for the future, memory boxes, and locks of hair.

50. Some helpful books for bereavement include, but are not limited to, L.K. Brown and M. Brown, *When Dinosaurs Die: A Guide to Understanding Death* (Boston, Mass: Little, Brown, 1996); M. Heegaard, *When Someone Very Special Dies: Children Learn to Cope with Grief* (Minneapolis, Minn.: Woodland Press, 1988); J. Silverman, *Help Me Say Goodbye: Activities for Helping Kids Cope When a Special Person Dies* (Minneapolis, Minn.: Fairview Press, 1999); R. Temes, *The Empty Place: A Child's Guide through Grief* (Far Hill, N.J.: New Horizon Press, 1992); A.D. Wolfelt, *How I Feel: A Coloring Book for Grieving Children* (Fort Collins, Colo.: Companion Press, 1996); M. Gellman and T. Hartman, *Lost and Found: A Kid's Book for Living Through Loss* (New York, N.Y.: Harper Collins, 1999); P. Karst*, The Invisible String* (Camarillo, Calif.: Devorss, 2001).

51. What does the appropriate involvement of children mean? Discussions about death, dying, and the care that a person wants to receive at the end of life are very sensitive topics. Children in the sensorimotor and the pre-

operational stages of development—children typically below seven years of age—are rarely cognitively capable of contributing to an ACP discussion formally. Children in the pre-operational stage do not understand irreversibility and have magical thinking. Thus, in discussions of ACP with children who are in the pre-operational stage, the children should be assured that discussing the possibility of death does not cause death to happen.

52. V. Larcher et al., "Making decisions to limit treatment in life-limiting and life-threatening conditions in children: A framework for practice," *Archives of Disease in Childhood* 100 (2015): s1-23; S.E. Zinner, "The Use of Pediatric Advance Directives: A Tool for Palliative Care Physicians," *American Journal of Hospice and Palliative Medicine* 25, no. 6 (2009): 427-30: G. Villanueva et al., "End of life care for infants, children and young people with life limiting conditions: Summary of NICE guidance," *BMJ* 355 (2016): i6385; World Health Organization, "WHO definition of pediatric palliative care," n.d., *https://www.who.int/cancer/palliative/definition/en/.*

53. A Durall et al., "Barriers to Conducting Advance Care Discussions for Children with Life-Threatening Conditions," *Pediatrics* 129, no. 4 (2012): e975-82.

54. Villanueva et al., "End of life care," see note 52 above, p. i6385.

55. J.D, Lotz et al., " 'Hope for the best, prepare for the worst': A Qualitative interview study on parents' needs and fears in pediatric advance care planning," *Palliative Medicine* (2016): 1-8.

56. A tool that may be helpful to clinicians in determining whether a prognosis is poor is asking, "Would you be surprised if this patient died in the next 3- and 12-months?" K. Burke et al., "The 'surprise' question in paediatric palliative care: A prospective cohort study," *Palliative Medicine* (2017): 1-8.

57. Lotz et al., " 'Hope for the Best,' " see note 55 above, p. 4.

58. E. Beecham et al., "Keeping all options open: Parents' approaches to advance care planning," *Health Expectations* 20 (2016): 675-84.

59. Clinicians and caregivers may be more apt to invite children to join discussions about care when their illness has been refractory to standard treatment, the available treatment options offer little curative promise or life-extending benefit, and they are nearing the end of life. R.C. Barfield and E. Kodish, "Pediatric ethics in the age of molecular medicine," *Pediatric Clinics of North America* 53, no. 4 (2006): 639-48.

60. J.D. Lotz et al., "Pediatric Advance Care Planning: A Systematic Review," *Pediatrics* 131, no. 3 (2013): e873-80.

61. L. Wiener et al., "Allowing Adolescents and Young Adults to Plan Their End-of-Life Care," *Pediatrics* 130, no. 5 (2012): 897-905.

62. J. Needle and A.R. Smith, "The Impact of Advance Directives on End-of-Life Care for Adolescents and Young Adults Undergoing Hematopoietic Stem Cell Transplant," *Journal of Palliative Medicine* 19, no. 3 (2016): 300-5; C.K. Ullrich et al., "End-of-Life Care Patterns Associated with Pediatric Palliative Care among Children Who Underwent Hematopoietic Stem Cell transplant," *Biology of Blood and Marrow Transplantation* 22 (2016): 1049-5.

63. J.W. Mack et al., "Care in the Final Month of Life among Adolescent and Young Adult Cancer Patients in Kaiser Permanente Southern California," *Journal of Palliative Medicine* 19, no. 11 (2016): 1136-41.

64. M.E. Lyon et al., "Family-Centered Advance Care Planning for Teens with Cancer," *AMA Pediatrics* 167, no. 5 (2013): 460-7.

65. M.E. Lyon et al., "A randomized clinical trial of adolescents with HIV/AIDS: Pediatric advance care planning," *AIDS Care* (2017): 1-10.

66. While clinicians may have more training and medical expertise, the values of patients and their families may not align with the medical diagnostic and treatment options. Navigating conflicts can be challenging and may require an ethics consultation.

67. American Academy of Pediatrics, "Section on hospice and palliative medicine and committee on hospital care: Pediatric Palliative Care and Hospice Care Commitments, Guidelines, and Recommendations," *Pediatrics* 132 (2013): 967.

68. Wiener et al., "Allowing Adolescents," see note 61 above.

69. M.R. Potthoff, "Go Wish-Pediatrics: Pilot Study of a Conversation Tool in Pediatric Palliative Care," *Theses and Dissertations* (2015): 1140.

70. "Shop Talk" was designed specifically for youth living with cancer, and is not for all children and advance care planning. Lori Wiener et al., "Shop talk: A pilot study of the feasibility and utility of a therapeutic board game for youth living with cancer," *Support Care Cancer* 19, no. 7 (2011): 1049-54.

71. R. Barfield et al., "Mind the Child: Using Interactive Technology to Improve Child Involvement in Decision Making About Life-Limiting Illness," *American Journal of Bioethics* 10, no. 4 (2010): 29.

72. Ibid., 29.