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Edited by Richard Hain, Ann Goldman, Adam Rapoport, and Michelle Meiring

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## **Children's views of death**

**Chapter:** Children's views of death

**Author(s):** Myra Bluebond-Langner, and Ignasi Clemente

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### **Introduction**<sup>1</sup>



Death is very much a part of the everyday thoughts of children. It is part of the games they play, the stories they hear, and the videos they watch. Sadly, for some children it is also part of their everyday lives—their lived experience in the face of a life-threatening illness, war, violence, or natural disaster.

Starting from the position that a child is a sentient, social, emotional, spiritual being embodied in a biological organism we look at how children's views develop, and how they are manifest in art, play, and conversations with family, friends, and professionals. We see children as active agents in their worlds—interpreting the behaviour of others and acting on the basis of those interpretations. Children see, sense, and notice, and correspondingly, register and make inferences from what they observe inside and outside of themselves. We attend not only to age and stage of development, but also to the dynamic relationship between age,

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stage, and experience as they come to bear on the children and their worlds at given points in time.

Working from this perspective we explore children's views of death and dying in a variety of situations, from a variety of perspectives—cognitive, cultural, social, and emotional—as a first step in developing guidance for talking with children who are themselves ill and dying, and their siblings. We address three questions and offers suggestions for talking with ill children and their siblings about death:

1. What do children know and understand about death and dying?
2. Where do children's ideas about death and dying come from?
3. How should we address their questions and concerns on this most fundamental question of human existence?

The chapter draws on an extensive review of the literature on well and ill children's views of death as well as the co-authors' ethnographically based research with ill children, their parents, siblings, and clinicians involved in their care and treatment; highlighting the social nature of death and dying (1, 2, 3, 4, 5, 6, 7, 8, 9).

### Children's views of death: A multi-dimensional, multi-faceted perspective



Children's views of death, like those of adults are multi-dimensional. They encompass not only the physical, but also the metaphysical, social, and emotional aspects. Going back close to 70 years ago and moving forward into the current decade the majority of studies of children's views of death focused on at what age and at what stage did children come to see death as an inevitable, final, irreversible process, that happens to all living things as the result of various biological processes.

While the particular age at which any of these concepts might emerge could vary, there was an assumption of linear development, which in the earlier periods of research was characterized as a movement from an 'immature' to a 'mature' view of death (Table 7.1).

Table 7.1 Developmental sequence of biological subconcepts of death

Death Subconcept	Definition of death subconcept	Age of acquisition (11)	Age of acquisition (12)
Inevitability	All human beings will die one day, death is inevitable	5	Combined with universality

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Irreversibility or finality	Death is final and permanent, once an entity dies, it cannot become alive again; death cannot be undone	5	5
Universality or applicability	Death applies to all entities that are alive, no living entity escapes death	6-7	6
Non-functionality or cessation	With death, all physical/ biological and psychological functions stop, a total cessation of all vital functions	6-7	6-7
Causality	Death is caused by the breakdown of bodily processes; understanding of events and circumstances that cause death	8-10, last subconcept to be acquired	6-7, last subconcept to be acquired with sophisticated understanding 9-10

Source: data from Panagiotaki G. et al. (2018). Children's and adults' understanding of death: Cognitive, parental, and experiential influences. *J Exp Child Psychol.* 166:96-115. DOI: 10.1016/j.jecp.2017.07.014; and Rosengren KS. et al. (2014). Cognitive Models of Death Monographs of the Society for Research in Child Development. *Monogr Soc Res Child Dev.* 79(1):83-96. <https://doi.org/10.1111/mono.12080>.

The notion of a stepwise linear progression ending in a mature view where scientific views of death are privileged over other aspects of one's view of death has been challenged on several fronts, including studies of adults themselves; evidencing views of death that would be considered immature (e.g. personifications of death—such as a gentle comforter, the

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Grim Reaper, or a wrinkled old woman, being taken into the splendour of heaven) (10).

Moreover, contrary to what the linear developmental model would suggest, religious beliefs introduced by parents appear to influence a child's views of death such that at the same time or not long after the child acquires or demonstrates a view of death grounded in the physical universe, they like adults, also offer supernatural views and perspectives which combine and/or rely on both supernatural and biological or physiological explanations (11, 12, 13, 14, 15, 16).

Kenyon in her extensive review of the literature on children's views of death found that *'despite clearly understanding most of the components of death by 6-years of age, religious teachings were reflected in Muslim girls' assertions, at all ages, that death was reversible and the dead could return to life'* (17, pp. 73–4). Similarly, in a study of children's ideas about death and the afterlife in Japan, children were greatly influenced by Shintoism, Buddhism, and Christianity, three major religious traditions in Japan (18). The children drew on various combinations of religious beliefs in perceiving the flow from life to life after death as either linear or circular.

Struck by the similarities to adults' views of death, children's views of continuity of life beyond biological death are no longer framed as evidence of magical thinking, but rather as the coexistence of explanatory models (12, 14, 16, 19). Notably, this allowance for coexistent explanations extends to encompass the ways in which children presented continuity of physiological functions (e.g. eating, sleeping in the grave) and emotional and mental states (feeling sad, sick) beyond the cessation of corporeal life (14, 16, 20).

The need to see and indeed examine children's views of death, not only in terms of religious beliefs and practices, but also in terms of the social and economic circumstances of their lives is well demonstrated when one reviews the findings of those who have studied and compared children from other cultures and societies outside the USA with those within it. For example, in a comparative study of children in a second grade classroom in Israel and the USA, Israeli children were clearer about the finality and irreversibility than children in a second grade classroom in the USA. However, the American children were more likely to perceive death as universal (i.e. all living things will die). The authors attributed these differences to the Israeli children's experiences living in the context of war, where they are regularly exposed to the finality of death, but also where adults try to comfort children (many of whom have fathers and siblings in the military) by telling them that not everyone dies (21).

Similarly, in a study of Kuwaiti (Muslim), American (Christian), and Indian (Hindu) kindergarten children, religion and nationality influenced the way in which they explained death and what happens to people when they die. For example, whereas some Indian and Kuwaiti children attributed death

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to poverty and hunger, no American children mentioned such causes. In addition, about 11% of the Kuwaiti children cited the Gulf War as a reason why people die (22).

In summary, this brief review of well children's views of death highlights what we need to consider in research and clinical practice when formulating a child's view of death. The importance of considering all of these aspects—age, varieties of epistemologies the child is working from (e.g. scientific, religious), cultural and societal context, experiences, who the child is speaking with, and how all of these parts fit together—is thrown into bold relief when we examine the views of ill children and their siblings.

### **Views of death in children with life-limiting conditions and life-threatening illnesses: Expressing their thoughts in words and deeds**



Bluebond-Langner first noted the need to look beyond the then accepted model for understanding children's views of death over 45 years ago when she found that age was not at all predictive of the children's views of death, their awareness of their condition, or the ways in which they communicated that awareness (1). For example, the 5-year-old boy who was concerned about separation, who talked about worms eating him, and who refused to play with the toys of deceased children was the same 5-year-old who knew that the drugs had run out and demanded that time not be wasted. So, too, the 9-year-old girl who drew pictures of herself on blood red crosses, and knew that the medication was damaging her liver, was the same 9-year-old who never mentioned the names of deceased children, and could not bear to have her mother leave her for a moment (6).

In each of these children, we find views of death as final and irreversible. We also note a concern about separation, coupled with causes of death ranging from a kind of contagion from dead people by mention of their names or play with their toys, to death as the result of a failure of the drugs used to treat the disease and lack of further available treatment. The girl suffers as did Jesus on the cross; for the boy the worms will eat him. Without a doubt these children are handling complex multifaceted, multi-dimensional views of death, shaped by their culture, their circumstances growing up in middle-class urban US, as well as care and treatment in tertiary paediatric hospital. Age does not accord here. Both of these children held to elements of what was then referred to as a 'mature view' of death as well as elements referred to as an 'immature view'.

Later studies by Bluebond-Langner et al. and by Clemente and others would support the position that children, like adults, are capable of simultaneously holding several views of death, even seemingly contradictory ones (2, 5, 16, 19). The particular view that emerges at any point in time reflects the child's momentary concerns, thoughts, and

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feelings, the person to whom they are speaking, and any other contextual elements that frame the particular interaction in which the view is elicited.

These additional studies not only provide insight into how the child fits these seemingly contradictory views together, but also how and why they emerge in thought and conversation. For example, in the following conversation we see Lakshmi, a 5-and-a-half-year-old child, born in UK of first-generation British Indian parents, using various bits of information to come up with a coherent and hopeful view of her prognosis in the face of predicted poor survival.

Lakshmi was diagnosed with juvenile myelomonocytic leukaemia (JMML) when she was 3 years old. After receiving aggressive chemotherapy and a bone-marrow transplant with donor cells from her mother, Lakshmi went into remission and was well for about a year. Then, at 5-and-a-half, she relapsed. Four months into her relapse, she causally told Bluebond-Langner, while they were colouring, *'Alexa died. You know her. She had JMML just like me. I am going to get more cells.'* Continuing to colour Lakshmi added, *'From my mom, and be all-better'* (4, p. 333).

In this exchange, Lakshmi displays an understanding of the cessation of bodily functions and of the causes that bring about death. Note that Lakshmi begins with the mention of someone who has died, Alexa. She makes an attempt to establish the cause through a statement or a hypothesis. JMML is the proposed cause of death. She compares the dead child to herself, but does not assume that just because they both have the same disease, she will die. Lakshmi holds out hope that she will recover, based on her previous experience, when she went into remission after receiving cells from her mother.

As noted in Bluebond-Langner's earlier work, while children can know of another child's death, in the absence of deterioration the child will not necessarily come to view herself as dying (1). While acknowledging the possibility of death from this disease one does not necessarily immediately apply it to oneself (see Maria's example discussed in the following section). The conclusion may emerge over time after several conversations. Tom was a 9-year-old boy with acute lymphoblastic leukaemia (ALL) for whom no further treatment or studies were available.

Tom: *'Jennifer died last night. I have the same thing, don't I?'*

Nurse: *'But they are going to give you different medicines.'*

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Tom: *'What happens when they run out?'*

Nurse: *'Well, maybe they will find more before then'* (1, p. 156).

In this conversation, we see a notion of death as the time when the chemotherapy would run out. Following this interchange, Tom's conversations about drugs and their side effects became less frequent. The drugs were not the answer that he and his parents had once thought them to be. As with other children who are aware of the prognosis, he made little reference to his condition or progress. What was there to say? There were only indications of further deterioration and closeness to death.

For these children, death is the result of a biological and inevitable process marked by steady deterioration:

As Louise, a 9-year-old with multiple relapsed ALL noted, *'I just get weaker and weaker, and soon I won't even be able to walk.'*

While Louise expresses her situation in physical terms, some children, use religious imagery. For example, in this brief exchange between Maria and her mother:

Maria is a 5-year-old Mexican American whose leukaemia is no longer responding to treatment and has gone home to die. Her awareness as well as her expressions and queries about death are bound up in reference to two other Mexican American children with leukaemia who had died.

Maria: *'Do children play in heaven?'*

Mother: *'Yes, yes they do.'*

Maria: *'Good, now I can play with Julio and Jorge'* (1, p. 190).

In this conversation, Maria displays an understanding of death as cessation, irreversible, and final. Julio and Jorge have gone somewhere else (i.e. heaven). They are not coming back. They are not 'becoming alive'. Like them, she is going to heaven. At the same time, she uses a notion of corporeal continuity—that something of who Julio and Jorge are, and who she is, continues in heaven after death. Recalling studies of adults noted earlier, the individual ascends into heaven and a part of

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one's life, in this case play, continues under changed circumstances. In death, life as mortals know it will be left behind.

Not surprisingly then, for these children, closeness to death also means having no future here on Earth. Conversations about the future decline noticeably; the future becomes limited to the next holiday or occasion. Children speak of Christmas presents in July, delaying treatment to enjoy Eid, and going to the shops to spend all of their savings.

Concerned about the time that they have left, they often push themselves to get things done (e.g. sit for exams, take part in the school play). Some children become angry when people take too long to remember things, or to answer questions, or to bring objects to them. Some children verbalized their fear of wasting time directly with phrases such as 'Don't waste time' or 'We can't waste time'. The staff often noted the activity and urgency that followed the death of a peer (6).

Parents and staff often comment on such behaviour. As one staff member commented:

*They demand because they know time is short. It's as if they know that if they wait too long, they might be dead by then. They're not just being difficult (1, p. 195).*

That staff member also stated that '*Those children know something.*' She pointed to Mary who was described in staff meetings as a 'demanding child' who never said anything directly about death or the possibility of dying to staff or her parents. Yet, when she died, her mother found a list of all the children who had died and the circumstances of their deaths as well as a 'kind of will'—a list of who she wanted to receive particular favourite possessions (1, p. 195).

With dying comes a loss of identity. Children with life-threatening and life-shortening illnesses feel that they are not like other children. For example, some speak of not getting braces, or clothes to grow into, or going to school—hallmarks of becoming, of being a child. Some no longer mention what they will be when they grow up and become angry if others do. For example:

*One child who, when first diagnosed, had said that he wanted to be a doctor became angry with his doctor when she tried to get him to submit to a procedure by saying 'I thought you would understand, Sandy. You told me once you wanted to be a*



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*doctor.* He screamed back at her *'I'm not going to be anything,'* and then threw an empty syringe at her. She said, *'OK, Sandy.'* The nurse standing nearby asked him *'What are you going to be?'* *'A ghost,'* Sandy said, and turned over (1, p. 194).

To speak of these markers of childhood as the children do indicates that the child knows that *they* have no future, that death is final. Death marks the end. The future is cut off. In short, stretching back into conversations with ill children about death we also find that dimensions of non-functionality or cessation of bodily function and finality are wrapped up in discussions of time and lack of future.

Woven through the children's formulations of their views of death, are the children's concerns about others. For example:

Caroline, an 11-year-old girl, with stage IV neuroblastoma from Gujarat (India), was living in Saudi Arabia with her mom who worked there. Caroline, who shared with her parents 'a strong Catholic faith', explained to the nurse that she had read her scan results, and had found online information about how children with multiple neuroblastomas in places like hers died. Aware of the irreversibility and finality of death, she told the nurse she was scared but trusted God would take care of her. When the nurse asked her if she had any more questions, Caroline said, *'Not for myself. I know God will look after me. But what happens to a family where there were two children and then there is only one?'* (23).

Their concern often is often expressed in ways we would not necessarily at first think of as indicating concern. For example:

Jeffrey was an 8-year-old boy with leukaemia who often yelled at his mother. When asked why he did this, he simply replied, *'Then she won't miss me when I'm gone.'* When I asked Jeffrey's mother *'Why does Jeffrey yell at you so much?'* she replied, *'He knows when I can't take it in that room any more. He knows that if he yells at me I'll leave. He also knows I'll come back'* (6, p. 58).



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### **Well siblings' views of death: Comparisons with ill siblings**

As death and disease are constants in the lives of ill children, so they are too in the lives of their well siblings. Hence, we are not surprised to learn from the study of well siblings of children with cystic fibrosis (CF) that their conceptualizations of death and their development are close to that of their ill siblings, with age not a major a factor and observation of their siblings and others with the same disease more prominent (7).

Like their ill siblings they see the disease as the cause of death. As one brother remarked:

*But I still get worried about my sister. I just know that with CF you could die from it and you get all skinny and your lungs fill up with mucus, and you can't breathe, and you die (7, p. 197).*

They too are acutely aware of the finality and irreversibility of that death, not to mention cause. As one well brother explained:

*My mom always asks me how come I never go down to the hospital to see them [his siblings who have CF]. I don't want to go to the hospital. I don't want to go down there and see them in the hospital. Not the fact that I don't want to go see them; it's just that I know what's going to happen. You know it's inevitable. You know the progression of the disease will get worse. That's inevitable (7, p. 211).*

While like ill children, they hold out hope, listing what can be done, at least for a time; they demonstrate a keen awareness of the inevitability of death. As a well sibling, whose sister now required oxygen during hospitalizations, commented:

*There are still things they can do. I'd worry with the oxygen and all, but I know Andrea's a fighter (7, p. 211).*

The disease is a despised enemy to be fought:

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*My sister has cystic fibrosis and I hate it. I wish there was a miracle—that they could have a medicine for cystic fibrosis. In their eyes, there is still room to do things (7, p. 210).*

Time and the lack of future loom large for well siblings just as it does for their ill siblings.

*She acts like she's gonna grow old someday and have a real nice car and stuff. [pause]. It would be nice but sounds impossible. Everybody never makes it, [pause] that far. All of her friends die. She thinks that maybe she'll beat it. I don't, but it's hard to say. Maybe she'll beat it (7, p. 211).*

Although well siblings may glibly link the terms 'incurable' and 'terminal', they do not necessarily internalize this as an outcome for their own brother or sister, at least not in the near future. There is an attempt to distance themselves, and their sibling, from the imminence if not the eventuality of death. Not surprisingly then, their views are often sprinkled with conditions and qualifiers:

*It's one of the deadliest diseases. You are in the hospital a lot. Your chances of surviving are almost zero. That's a lot, really scary (7, p. 210).*

It is important to note that recognition and acknowledgement that their own sibling will die from the disease can vary amongst well siblings, including those within the same family, as illustrated in the following conversation between two well sisters of a recently deceased brother:

*Roberta: Right up until the end, even with the morphine I didn't quite get it together that Reggie was really going to die then. Sally and the others [other family members] could, even before, but not me. But then I wasn't as close to Reggie as Sally was.*

*Sally: I knew he was dying probably before anyone else, probably even before my mother, because I talked to Reggie about it (7, p. 257).*

Without speaking, they could maintain distance from the imminence if not the eventuality of death.

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Roberta: *I was afraid to talk to him because I didn't want him to tell me that he was dying. I didn't want to talk to him because of that. So I would go in and he'd be in his room, on oxygen, and I would talk to him, but I would never—you know I didn't want it to get to the point where he would start telling me "You know it's going to be over soon" (7, p. 257).*

Much as they might want or even try to avoid the finality of death and its frank irreversibility, they knew otherwise, as is also evident in this mother's recollections:

Even when Ethan died, Ian [his well brother] knelt by the bed and said "*He isn't dead:*" He knelt by the bed and said "*See, he's still here*". Ian would come home every day after school and say how much better Ethan looked. He'd go "*See how much better he is*". I had to shake him and say, "*He isn't going to get better*". But he knew that. His teacher told me he knew (7, pp. 259–60).

### **Talking with others about death: Conversations between ill children, their parents, siblings, and clinicians**



#### **Prevalence of mutual pretence in conversations**

For both well siblings and children with a chronic life-threatening illness, communicating with each other, as well as with their parents and clinicians about the illness and death is problematic throughout the course of the illness, and especially so at the end stages of the illness. Conversation about the illness and death is often shrouded in *mutual pretence*.

In the practice of mutual pretence, each party knows what is happening but neither of them wishes to speak about or acknowledge it to the other. In the context of mutual pretence, as outlined by Glaser and Strauss in adults (24), and later by Bluebond-Langner in children (1), dangerous topics are avoided, safe topics dominate the conversation, and an individual provides a way for the other party to abandon the conversation if it appears likely that the pretence will be shattered. Behaviours, such as avoiding discussion of the future, displays of anger, withdrawal, and engaging in banal chit-chat which offers people an excuse for leaving all reflect adherence to these rules.

In mutual pretence, there is, as Dixon-Woods et al. note '*unvoiced agreement that the prognosis will not be discussed*' (25, p. 74). They find

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the construct 'emotional labour' (25, p. 74) useful as 'children may engage in work to protect their parents' well-being' (25, p. 74), to which we would add that of their sibling's as well. As one ill child remarked, when discussing why she did not talk to her well brother about her condition.

*He worries a lot. He worries about me mostly. I don't know why. Sometimes he talks to me about what he worries about. Sometimes I wouldn't say much because he doesn't want me to know. He just, well, I can hear it on the phone that he is [worried] (7, p. 252).*

Well siblings are similarly concerned. One of them commented:

*I don't think I'd be able to talk about it. I might say something that would get her mad or upset. I'm really scared about what her reactions will be. Maybe something would come up that my parents don't want her to know. I don't want to tell because I don't know what is going to happen. I don't know how she is going to react. I don't know if she's just going to say, "Well, when it happens", or if she's going to start crying or something like that (7, p. 251).*

Siblings' reluctance to speak often occurs when they are fully aware that the ill sibling not only knows the prognosis, but also knows that other people are unwilling to talk about it. As one 12-year-old sister commented:

*I think she sort of feels out in the cold about that we know more about it than what we're telling her. I think she knows, from the people that we have known who have had CF and died. We haven't said "That kid had cystic fibrosis", or anything like that. We sort of say "It's a shame" and leave it at that. We don't really tell her. But she knew one [who died] and that he had treatments like her (7, p. 251).*

The struggle over what to say, let alone do, remains problematic right up to the moment of death, as can be seen in the following conversation between two sisters recalling the time of their brother's death:

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Mindy: *Just like before he took it [the morphine], he asked us. He said uhm ... it was just you [Faith] and I there. And he said, "Do you think I'm a real asshole for doing this [taking the morphine, which might bring on respiratory failure and death]?" You wanted to say "Yea, don't do it." But that would have been for us.*

Faith: *And the kid couldn't breathe, as it was [he had been on oxygen for quite some time].*

Mindy: *And I could see you [Faith] were just about to tell him not to do it.*

Faith: *Oh God, it was on the tip of my tongue, "No! No! No!" But I was ....*

Mindy: *That was hard.*

Faith: *Yeah, that was hard. He didn't want us to think he was copping out like he wasn't a survivor. He couldn't breathe. I mean he was saying goodbye to us and he couldn't even breathe (pause). It was the hardest thing. He didn't want us to think that he was giving up.*

Mindy: *We knew that he had to do it. And we were all there with him. And we all did get to say goodbye. How many of us will get to say goodbye to everybody before we go? (7, p. 259).*

The 'protection' is often appreciated. One well brother summarized the feelings of many when he said:

*We don't talk about it. I try to stay away from it, because I don't like to hear it. I already know for a fact what's going on. I know as much as I need to know. I don't care to hear any more about it. If they come up with a cure that's great. Then I won't have to worry about it all. But they haven't, so we don't talk about it (7, pp. 245-6).*

We would also suggest that to receive confirmation of their sibling's fate and then to talk about it raises a host of problems for well siblings, not least among them the ability to ask for and make demands directly from their parents (7).

The 'emotional labour' is reciprocal. Each endeavours to protect the other. We see this in the case of children with their parents as well. It can emerge in discussions of further treatment or perhaps in some ways more

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troubling with regard to pain. In studies as well as in clinical practice in USA, UK, Kuwait, children have been observed to keep their pain from their parents (3, 4, 5, 8, 9, 23). For example:

One morning when the home care/hospice nurse asked Stephen, a 6-year-old with multiple relapsed disease what makes him feel better he said: '*Pushing the button,*' referring to the morphine pump. He also told her, '*Don't tell my mother.*' When the nurse asked him why he told her, '*So she doesn't get worried.*'

When the children do engage with their parents in a conversation about death they are careful to do so in a way that their parents can handle. So as Clemente has found in his work in Spain with children whose parents, and in many cases the children as well, have a deep religious faith, discussions of death between parent and child are often replete with religious imagery (9). For example:

Eli, a 5-year-old girl from Colombia with relapsed Wilms' tumour with lung metastases and failed autotransplant, treated in Catalonia Hospital, talked repeatedly with her mother about angels and heaven as well as Jesus' passion and death. As a bedtime story, Eli would ask her mother to tell her the story of how Jesus died, asking her mother all kinds of details about how they placed the crown of thorns on Jesus' head and how he was crucified. Eli told her mother that Jesus did not cry because he knew he was going to heaven. However, Eli also puzzled her mother with questions about why Jesus did not do anything to save himself.

Religious imagery can also be a way that children communicate about their emotional state, their anxiety and fear. Consider Felipe:

Felipe was an 18-year-old, with papillary thyroid carcinoma and metastases who had relapsed numerous times over for 6 years and who was now experiencing difficulty breathing. In order to improve his breathing, the doctors and his parents had agreed that Felipe would be hospitalized for 'a series of palliative chemotherapy sessions'. Knowing 'how terrified' Felipe was about chemotherapy they decided not to tell him that he would receive chemotherapy when admitted to the hospital. When the doctors met with Felipe and his parents hours before starting chemotherapy, Felipe complained that his parents had not told him anything at all. Felipe's mother recounted how the night

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before Felipe had said that, *'he felt like Jesus during the last supper ... like Jesus before he was handed over to be crucified'* (9).

Our purpose here is not to argue for or against mutual pretence but rather to underscore how deeply embedded death concepts, the cognitive if you will, are embedded in the social—the interactions among people who care deeply about each other. Through each individual's choice of topic and the way they speak about it, each acts to preserve the identity of the other—the child as one who will become, the parent as nurturer and protector, the clinician as healer. In this way interaction can proceed. Moreover, failure to recognize mutual pretence, as well as why it may be occurring, can lead to interventions that while undertaken with the best of intentions can lead to harm. So, what is a clinician to do?

### **Addressing mutual pretence with parents and children: Shuttle diplomacy or arbitration model**

Addressing mutual pretence, as alluded to earlier is not only about the child's well-being, but also that of the family, particularly that of the parents' so that they can continue to fulfil their roles as nurturers, protectors and advocates (1, 4, 8, 9, 26, 27). For example:

For Jeremy, a 14-year-old boy who was treated 14 months earlier with radiation and chemotherapy for a then partially resected anaplastic astrocytoma that now how had recurred, the only disease-directed option available was a Phase 1 clinical trial. His father did not want him told that it was a trial or anything much else about it. His mother on the other hand was willing to tell him about the drug, but not that it was a trial. She explained, *'We felt like telling him it's a clinical trial, but that sounds so harsh. We never did use the word trial. We didn't want him to think that it was some kind of experiment. You know, sometimes experiments don't work. He is only 13, 14 in 3 weeks. We just felt like this was something that he didn't have to know.'*

*'Jeremy knows he has cancer. He knows people have died from cancer, but we try to have him rely on faith. You have people praying for you, you pray for yourself. It doesn't necessarily have to mean that you know, but that he knows'* (4, p. 328).

At times such as this, parents may not wish to discuss various aspects of proposed treatment or death with their child, or to have anyone else do so. In such situations it is extremely important, as well as beneficial, for clinicians to pursue with the parents why they do not want particular



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information to be shared with the child to learn information about the family's rules, communication patterns, spiritual beliefs, roles, and previous experience of death. When talking with parents about what they do not want their child to know, the physician also becomes aware of misunderstandings about various care and treatment options, such as prognosis or other issues in the family, that may be affecting the choice of care (4). Continued discussions with the parents about what they do not want to have discussed with their child are an opportunity that should not be missed.

The clinician may open the dialogue with the parents by acknowledging that she appreciates their views. In the course of the conversation, the clinician might note that, on the basis of her experience, the child already knows the likely outcomes. She might give some examples of the ways in which children indicate their desire to know more from their parents, as well as the cues that children give which indicate what they know, and their desire for more information.

The clinician might ask the parents what they would most fear if the possibility of dying or the efficacy of other treatment alternatives were to come up. The physician might suggest that perhaps further discussion with the child, either with the parents present, or with the clinician alone, would be helpful for all of them—and if not now, then perhaps in the future.

The parents may continue to refuse to have discussions with the child about particular issues, or even to allow the clinician to have discussions with the child that would include the child's prognosis, or the side effects, or efficacy of various types of treatment, but even so the groundwork will have been laid for further discussions, and insights might have been gained that will serve the clinician well in other situations as they arise with the parents and their child.

### **Suggestions for discussions with children about death and dying**



In assessing a child's understanding of death, indeed in talking with children we must proceed with an awareness of the social, relational, cultural, and emotional factors that are in play whenever the subjects of death or dying are before the child. We must look beyond age and verbal presentations for indications of the child's conceptions of death. Their perceptions and perspectives are not fixed. They are fluid, in process, and as such subject to change. From this perspective, several general suggestions for talking to well and ill children about death emerge (see Table 7.2).

Table 7.2 Talking to children about death and dying

<b>Dos</b>	<b>Don'ts</b>
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- |   |  |
|---|--|
| <ul style="list-style-type: none"><li>• Listen first.</li><li>• Take cues from the child.</li><li>• Take stock of your own beliefs and anxieties.</li><li>• Talk in terms that the child can understand.</li><li>• Be concrete.</li><li>• Pace your explanation.</li><li>• Elicit clarifying information before responding to the child's questions.</li><li>• Ask the child to repeat back what has been said, in order to make sure that they have understood it.</li><li>• Share literature for children appropriate to the situation at hand.</li><li>• Consider using creative activities such as drawing, painting, storytelling, and puppet shows to help to facilitate discussions.</li><li>• Reassure the child that they are loved, will be cared for, and will not be abandoned.</li></ul> | <ul style="list-style-type: none"><li>• Do not equate age with understanding.</li><li>• Do not regard the concepts of disease or death as fixed.</li><li>• Do not assume that children do not know about death/are not aware of the signs just because they don't verbalize their knowledge or awareness.</li><li>• Do not use euphemisms or overly complicated explanations.</li><li>• Do not make assumptions about what a child is asking.</li><li>• Do not assume that one conversation will be enough.</li><li>• Do not say what you do not believe.</li><li>• Do not be afraid to say, 'I don't know'.</li></ul> |
|---|--|

Above all, listen to the child. Discussions with children about death begin with listening. Take your cues from the child. Both when you are listening and when you are speaking, bear in mind the following points.

- Children are keen observers; they have the ability to learn about death whether or not we choose to tell them.
- Children have fluctuating needs and desires at different points in time.
- Children can simultaneously hold scientific as well as other worldly or religious views of death.
- Children desire to keep those whom they care about around them, which can lead them to follow the conversational rules that we set up.

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If a child senses that someone is uncomfortable talking about death, the chances are that he or she will not pursue the discussion. It is important that our responses are driven by the child's thoughts and concerns, and not by our own, which may be rather different. We need to talk with children about what they want to know in terms, which they can understand, and consequently, it is important to be concrete and avoid complicated explanations. Pace your reply. Do not make assumptions about what the child is asking. A question such as 'How does chemotherapy work?', may be a request for more information about drug activities and cells, or it may reflect a deeper concern about the efficacy of the treatment.

We want to uncover the intention of the child's question or remark. What is the child really asking about and wanting to know? Asking clarifying questions in return may be helpful when responding to a question for which the intention is unclear.

It may also be helpful to preface your remarks with statements such as 'That's a good question', or 'I would really like to talk with you about that', signalling to the child that we are happy to pursue the conversation whatever direction it takes. Perhaps nowhere is this more necessary than when responding to an ill child who asks, 'Am I going to die?'. More often than not, when a child asks this question they already know the answer; we can seize this opportunity to explore with the child their thoughts, fears, desires, and concerns—be they about pain, treatment, family relationships, or meaning.

Very young children can experience a deep sense of loss, can mourn, and understand or at least have feelings about what it means to die. They can also understand more than their verbal statements would indicate.

Some researchers and clinicians have suggested the use of children's literature as a way both to elicit children's thoughts and feelings about death, and to help them to cope with the attendant anxiety and feelings of isolation. Discussion of stories with an adult can provide an opportunity for children to have their questions answered, acquire more information, and engage in creative problem solving. Other methods include talking about death through additional 'child-friendly' activities, such as drawing, painting, storytelling, and puppet shows, as well as everyday play. Creative arts, in particular, are thought to offer children a symbolic means of expressing painful, frightening, or embarrassing feelings (28, 29).

All of these activities allow children to engage with death as a topic of discussion indirectly, but still to have their questions heard and their needs attended to by a supportive adult. Because of the social taboos regarding open discussion of death, these approaches may make this a more comfortable method of communication for children and adults alike.

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It is important to bear in mind that children share different kinds of information with different people at different times. For example, what children say to the priest about death is different from what they want to talk about with the physician or their parents. A child may share feelings with a friend or teacher but not with their parents, lest they upset them. Clinicians and other adults attending to a child's well-being need to be especially alert and prepared, as children may feel that they can ask questions and discuss death more freely with a more 'neutral' person than with family members.

One conversation is not necessarily enough. The child's desire to talk about death, whether they are well or ill, will not necessarily disappear after one discussion. Children want to know different things at different times. There will be different questions and concerns in the face of different experiences. As various new experiences are processed, the issues that they raise need to be addressed.

### **Talking about death with bereaved children: An additional note**



A child's way of expressing loss may be quite different from that of an adult or what an adult would expect. For example, when Amy's brother died, she loudly declared '*Good, now I can have all his toys*' (6, p. 63). Obviously, there was more there than the statement would suggest. Children can be sad one minute and out playing the next—this does not mean that the child does not hurt or does not need someone to talk to. We must bear in mind that children are often frightened by adult displays of grief, and they need reassurance.

Children may ask questions that we regard as obvious or in some cases even offensive, such as 'Well, how did they know that Grandpa was really dead?', or 'When will you die?'. Some children have a real passion for gory, macabre details. Given the opportunity, children at a wake will often touch the corpse and ask about embalming—not necessarily the kind of behaviour that adults would engage in. Although such behaviours may be the result of simple curiosity, they may also be an attempt by the child to reaffirm their relationship with the deceased. As such, the use of projects such as memory boxes may be especially helpful to bereaved children, serving as a 'linking object' that helps to maintain and foster the connection to the person who died (see also Chapter 13).

### **Conclusion**



Studies, past and present, demonstrate the need to understand children's views and approaches to talking and dealing with death in the context of their family, the cultures and communities in which they live, their religious practices, and their belief systems. Clinical practice would benefit from further study of children's views of death as they emerge in conversations, not only with researchers, but also with clinicians and parents. We need to know far more than we currently do about what

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children with conditions other than cancer think about death and how they wish to be spoken to.

As we proceed in future research and look to incorporate research into practice we need to focus on the on-the-ground interactions between children, parents and clinicians. We also need to recognize and situate our work and our recommendations in the world that ill children now enter—a world marked by ever-increasing advances in medical science and technology, rapid access to information as well as misinformation. We need to be alert to both what children bring with them before they became ill as well as the new world they encounter, living and dying with a life-limiting condition.

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### Notes:

1 In order to protect the identity of research participants, 1) institutional and personal names have replaced with pseudonyms, and 2) some biographical information, such as the child's place of origin and residence, has also changed.