

Original Article

Cite this article: McPoland P, Grossoehme DH, Sheehan DC, Stephenson P, Downing J, Deshommes T, Gassant PYH, Friebert S (2024). Children's understanding of dying and death: A multinational grounded theory study. *Palliative and Supportive Care* **22**, 213–220. <https://doi.org/10.1017/S1478951523000287>


Received: 04 April 2022
Revised: 07 February 2023
Accepted: 26 February 2023

Keywords:

Children; Death; Qualitative; Grounded theory; Cross-cultural

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Abstract

Objectives. The ways in which children understand dying and death remain poorly understood; most studies have been carried out with samples other than persons with an illness. The objective of this study was to understand the process by which children directly involved with life-limiting conditions understand dying and death.

Methods. This qualitative study obtained interview data from $N = 44$ 5–18-year-old children in the USA, Haiti, and Uganda who were pediatric palliative care patients or siblings of patients. Of these, 32 were children with a serious condition and 12 were siblings of a child with a serious condition. Interviews were recorded, transcribed, verified, and analyzed using grounded theory methodology.

Results. Loss of normalcy and of relationships emerged as central themes described by both ill children and siblings. Resilience, altruism, and spirituality had a bidirectional relationship with loss, being strategies to manage both losses and anticipated death, but also being affected by losses. Resiliency and spirituality, but not altruism, had a bidirectional relationship with anticipating death. Themes were consistent across the 3 samples, although the beliefs and behaviors expressing them varied by country.

Significance of results. This study partially fills an identified gap in research knowledge about ways in which children in 3 nations understand dying and death. While children often lack an adult vocabulary to express thoughts about dying and death, results show that they are thinking about these topics. A proactive approach to address issues is warranted, and the data identify themes of concern to children.

Introduction

The ways in which children directly involved with life-limiting conditions understand dying and death remain poorly understood. Most studies explaining children's understanding of dying and death report the perspective of surviving, bereaved parents (Kennedy et al. 2018; Sheehan et al. 2014, 2019, 2016; Vázquez-Sánchez et al. 2019). Pediatric palliative care (PPC) research has primarily explored parental or provider perspectives (Singh et al. 2015; Spruit et al. 2018). The paucity of literature exploring dying and death from seriously ill children's self-perspective presents a significant gap, given that nearly 8 million children worldwide would potentially benefit from PPC (Connor et al. 2017).

In 2015, the International Children's Palliative Care Network conducted a Delphi study with 758 international, multidisciplinary members from 52 countries identifying PPC research priorities. Of the 70 research areas presented to respondents, the need to “understand death and dying” emerged as the top priority, illustrating both the urgency with which PPC providers require better evidence to guide care for seriously ill children and the continued silence of the affected child's voice (Downing et al. 2015).

Researchers have sought to understand the childhood cancer experience from the child's perspective but have not explicitly focused on how children process dying and death while struggling with, or watching a sibling struggle with, other life-limiting conditions (Bjork et al. 2006; Vindrola-Padros 2012). Children's understanding of dying and death differs from that of adults

in numerous ways, including age, developmental stage, prior experiences with death, and illness variables (diagnosis and time since onset), as well as cultural, religious, and familial beliefs (Panagiotaki et al. 2018). How living with the illness in themselves or their sibling affects their understanding of dying and death remains unclear. This study's purpose was to understand how children process dying and death in 3 cultural contexts to ensure that PPC services can meet the needs of children and families in culturally competent ways.

Methods

Participants

Approvals were obtained from the institutional review board at a hospital in the Midwest USA where it was carried out, the Hospice Africa Uganda Research Committee, the Uganda National Council of Science and Technology, and the National Review Board of Bioethics from the Health Department of Haiti. These countries were chosen to provide diverse locations because the investigators had relationships with local collaborators, facilitating the identification of potential participants and fulfilling local ethical review processes. Participants were children who received care through one of 3 sites in the USA, Haiti, and Uganda or were a sibling of an enrolled US child with a serious illness. Children were eligible if they were 5–18 years old with life-limiting conditions (Uganda, 8–18 years), were able to assent, had a caregiver providing consent, had a Karnofsky/Lansky score of >50, were developmentally able to express themselves, and had the stamina to be interviewed. Siblings were included as the conceptualization of the project was to assess and compare how children with exposure to the medical community, either in themselves or in their family, understand dying and death. Also, in many cases, the patients themselves did not have the ability to participate due to an underlying diagnosis of severe neurologic or cognitive impairment. While the intent was to have siblings in all countries participate, for safety reasons in Haiti, this was not possible.

Procedure

Families were approached by a member of the research team who informed them of their eligibility and offered to further describe the study to them. Haitian participants over 10 years old were aware of their diagnosis. Ugandan participants knew their diagnoses in some, but not all, cases. US participants were normally aware of their diagnoses. After obtaining informed consent, 28 individual semi-structured interviews (which included a collection of demographic data) were conducted between March 2016 and December 2018 in the hospice/hospital where the child received care or in the child's home. Interviews were conducted in the USA and Haiti by P.M. and overseen in Uganda by J.D. Sample questions included, "Have you ever known anyone or been around someone who has died?"; "What happens to a person after s/he dies?"; and "Do you believe people/animals have souls?" (see Supplementary material for the complete interview guides). The core analytic team included 1 doctorally prepared PPC scientist with pediatric chaplaincy experience and 2 doctorally prepared nurse scientists. A medical interpreter was used for Haitian children when English was not their primary language to ensure accuracy and understanding. Children in Haiti were interviewed by a medical interpreter in Creole (required by the national bioethics committee); Ugandan children were interviewed by nurse researchers

who spoke Luganda and Madi. Semi-structured interview guides with specific probes and focused questions directed conversations with the children to ensure inclusion of key areas for discussion. Interviews and field notes were digitally recorded, translated into English when necessary, and transcribed verbatim. The interviewer reviewed each transcript for accuracy. NVivo 12.0 was used to manage the data.

Analysis

The investigators used grounded theory methodology to understand how ill children and their siblings process dying and death from their own perspectives. Grounded theory is a qualitative method of iterative and inductive strategies that guide researchers in understanding the social processes of a specific phenomenon. Systematic analytic procedures lead investigators to produce an explanatory or theoretical model of the phenomenon that is "grounded" in the data itself, giving voice to the participants immersed in the experience (Charmaz 2014). Data from interview narratives and field notes were analyzed using grounded theory methods to focus on how children processed dying and death using constant comparison analysis to compare emerging codes across transcripts. Four levels of coding (i.e., line-by-line, focused, axial, and theoretical) were used to transform the data into an explanatory model (Charmaz 2014; Glaser 1978; Strauss and Corbin 1990). During first-level coding, any phrases, sentences, or paragraphs revealing information related to the coping strategies of adolescents were labeled with code words that captured the essence of participants' remarks. The participants' words were used as labels when possible. A list of codes was developed, and display grids were used to organize codes attributable to the 2 participant groups. Several procedures were used to enhance the trustworthiness of our findings (Lincoln and Guba 1985). The perspectives of the children and their siblings were used to construct the explanatory model. The analysis was conducted by an interdisciplinary research team. Each member analyzed the data individually followed by peer debriefing and discussion of emerging findings during data analysis until a consensus was reached. All methodological decisions were documented in an audit trail.

Results

Demographic data for the participants are presented in Table 1. A theoretical model explaining how this sample of children from 3 geographical and culturally diverse regions processed serious illness, dying, and death emerged from the data (Figure 1). *Loss* emerged as a central theme described by both ill children and siblings. *Resilience*, *altruism*, and *spirituality* were used by ill children as strategies to manage their losses and *anticipated death*. Major themes and exemplars are presented in Table 2.

Loss

Loss was a central theme, with loss of others and loss of normalcy emerging as 2 subcategories of losses most often described.

Loss of others

Culturally distinct differences were identified. Haitian children were more likely to witness another child's death because they were hospitalized in larger wards and therefore nearby when a child died. Although witnessing another ill child's death was not

Table 1. Participant demographic characteristics

		N (%)	M (SD)	Mdn (Range)
Child with disease, <i>n</i> = 32	American	8 (40)		
	Haiti	10 (100)		
	Uganda	14 (100)		
Sibling, <i>n</i> = 12	American	12 (60)		
	Haiti	0 (0)		
	Uganda	0 (0)		
Gender (female; <i>N</i> = 44)	American	10 (36)		
	Haiti	4 (14)		
	Uganda	14 (50)		
Age (years), <i>N</i> = 44	American		11.8 (3.8)	11.5 (6–17)
	Haiti		9.3 (4.0)	8 (5–15)
	Uganda ^a		12.7 (3.5)	12 (8–18)
Primary diagnosis of child with disease, <i>n</i> = 32	Cancer	16 (47)		
	HIV	8 (23)		
	Epilepsy	1 (3)		
	Sickle cell disease	1 (3)		
	Neurological/neurodegenerative	2 (6)		
	Congenital/chromosomal abnormality	1 (3)		
	Immunodeficiency disorder	1 (3)		
	Trauma	1 (3)		
	Complex care	1 (3)		
Race, <i>N</i> = 44	Caucasian	17 (39)		
	Black	27 (61)		
	Orthodox	1 (4)		
Religious affiliation (the USA and Haiti only; <i>n</i> = 24)	Protestant	18 (75)		
	Roman Catholic	4 (17)		
	Orthodox	1 (4)		

^aOne participant did not know his age and was not included in the calculation of the mean age of Ugandan participants.

distressful for all participants, most described the experience as “sad,” “uncomfortable,” or “scary.”

Ugandan children were more likely to experience the serious illness or death of a parent. An 8-year-old Ugandan girl recounted

her father’s death from 3 years earlier: “My father died when I was five years old, many people come and he was buried in the soil. People were crying and I also started crying but my Aunt took me away at that time. He died because of sickness – of HIV.”

American children typically described the loss of family elders (e.g., grandparents) and saw their deaths as expected with statements like, “because he was old” (9-year-old US male) or “she was sick and she was old ... she looked peaceful so it wasn’t as hard” (14-year-old US female). Because they had prior relationships with the deceased relative, several participants found comfort by focusing on positive traits. For example, a 17-year-old American male remembered his great-grandmother as “independent – she didn’t really rely on anyone to do things for her ... I admired that.”

Loss of normalcy

Losses of normalcy included the loss of health, school, time with friends, and activities. Perceived loss of health often led to other types of loss, such as for a 15-year-old Haitian male who could not play soccer “... when I was sick.” The loss of health obstructed the routines of the ill child and siblings. Similarly, a 14-year-old American female said her brother’s illness kept her from “... hang[ing] out with my friends as much as I would have like [*sic*] to.” The loss of health obstructed the routines of the ill child and siblings.

The seriously ill children from all 3 cultures missed attending school and spending time with friends. A 17-year-old US male said, “I remember crying about not seeing my friends and then I thought I might be able to go back later to school but I ended up not being able to.” Several Ugandan children reported being bullied at school by their peers or teachers when peers or teachers feared the child’s diagnosis. A 9-year-old female described being “chased from school” which made her “feel bad”: “When I go to school, children begin abusing me and telling me that [I] am infectious and even teachers don’t like me. They normally chase me away from class and even when [I] go for prayers I sit outside.”

Several American and Haitian children said that they missed participating in sports. A 15-year-old American male described how pain kept him from running like he used to. He said, “... I don’t like to run now because it hurts” and wished he could “trade my body for the weekend.” Siblings were affected by the illness when they assumed more home responsibilities because parents were at the hospital. This interfered with the healthy sibling’s activities, such as a 12-year-old American female who missed cheerleading practices because of her brother’s illness.

Resilience

Resilience was used by several older children as a process to manage their loss and anticipate death. Resilience, which may differ across cultures, is an adaptive response to stress in which the individual is able to recover from the stressor (Rutter 2012).

Resilience and loss

Several processes in this model were deemed bidirectional when data showed that each variable influenced the other. For example, data showed that the process between loss and resilience was bidirectional (i.e., resilience influenced loss and loss influenced resilience). Resilience appeared to affect how participants experienced loss if they could see their situation positively or as a new normal. A 17-year-old American male referred to his illness as, “It’s just a fact of life at this point. It’s become such a subconscious thing like breathing to me....” However, there were still times when

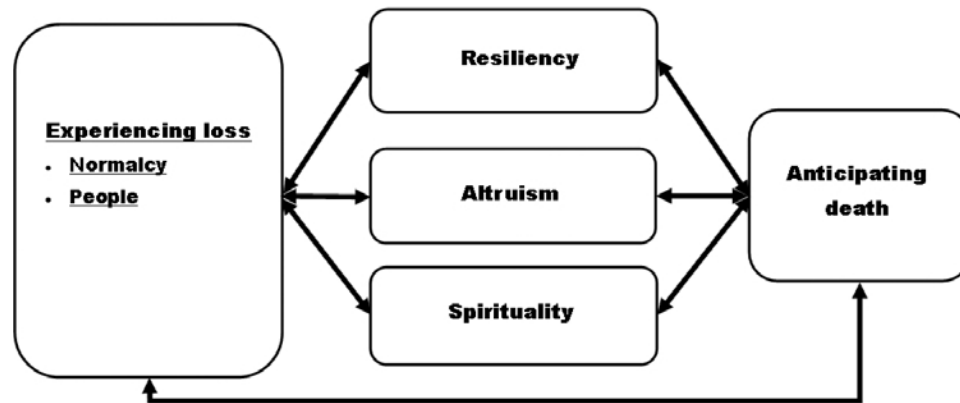


Fig. 1. Children's understanding of dying and death.

he was less certain: “[there are] certain things I still don’t want to accept like not being able to walk. I accept it but I don’t accept it.” A 15-year-old American male described his resilience as “there’s a big journey in life. I’ve been getting more aware of things and how I’m going to react to them. Sometimes I’m bad at reacting to them but over the years I’m getting better and better.” When asked to explain what types of things he has learned, he said to “... be aware of the surprises in your life.”

Resilience is about adaptation, and several children discussed how they adapted from their losses. A 17-year-old American male stated, “I kinda had to grow up faster – I think it made me a stronger person. I’ve become more determined to get stuff done. The positives definitely outweigh the negatives.”

Resilience and anticipating death

Data showed that the process between resilience and anticipating death was bidirectional. Anticipated death refers to the uncertainty that participants had about whether the serious illness would ultimately take the patient’s life, and if so, when. Resilience influenced how participants anticipated death. A 15-year-old Haitian male explained, “... to live a good life I have to pass this situation. I have to pass this moment.” His belief that “this moment” could be overcome shows his resilience adapting to new situations. Conversely, a 13-year-old Ugandan female showed that anticipating her death had a negative influence on resilience, because as she said, “I fear death because I still have things to do.” A 15-year-old American male kept a positive attitude despite knowing that he could die. “It’s not fun and every day you think you’re not gonna wake up, but you just thank the Lord every day that you are woke up and you try to have a good time.”

Altruism

Altruism is motivated by compassion and empathy and occurs when someone commits to improving someone else’s welfare. Several children used altruism to process their loss or anticipate death.

Altruism and loss

Data showed that the process between loss and altruism was bidirectional. Altruism influenced how loss was experienced by children wanting to do good deeds for others despite their own loss. A 15-year-old American male wanted to help others although not feeling well himself: “Almost every day I feel tired because of my

medicine but I like to make people happy ... I like to joke around a lot.” In another example, a 7-year-old American female did not discuss her great-grandmother’s death because “my grandma cries when I talk about her.” For her, not discussing death was something nice she could do for her grandmother. Loss also influenced altruism when children did good deeds for deceased family members, such as a 9-year-old American female who “... prays for [her deceased grandfather] at night.” This girl continues to be committed and motivated to improve her grandfather’s well-being, even after death.

Altruism and anticipated death

Altruism and anticipated death were evident in a 15-year-old Haitian male who witnessed another child’s death. Rather than focusing on himself during the stressful time, he opted to say a prayer of protection for the other children as well: “Pray for those that are still living not to pass the way the kid that died passed.” This was a profoundly altruistic act when it would have been understandable to think solely of his own health and well-being. A 16-year-old Ugandan male provided a good example of how his anticipation of death led to altruistic acts for others. He taught other youth “about HIV and how we can prevent ourselves because when I teach the youth, it gives me hope that ... we shall reduce the number of children who get HIV.”

Spirituality

Spirituality was used by several older children to manage loss and anticipate death. Spirituality is defined according to the dimensions of meaning, beliefs, connections, self-transcendence, and value that interrelate to form the essence of spirituality (Stephenson and Berry 2015).

Spirituality and loss

Data showed that the process between loss and spirituality was bidirectional. Spirituality influenced how loss was experienced when spiritual beliefs provided comfort for loss. A 12-year-old American female explained this best when she described the loss of her grandfather: “I cried just a little bit because I knew he would be safe wherever he’s going – like heaven.”

Loss also reinforced spiritual beliefs for a 13-year-old American male who attributed the unusual events in his home to a continued bond with his deceased grandmother. A story about his mother’s wedding ring showed the extent to which he believed his

Table 2. Major processes and exemplar quotations

Major process
1. Resilience and how loss is interpreted inform each other
1.1 "It's kind of just a fact of life at this point. It's become such a subconscious thing like breathing to me.... All the other kids would be outside dressed up in their [cold weather] gear but now that I'm older and I understand it more, it's just like, 'Yeah, it's cold today, I'm not gonna do it.'" (17-year-old American female)
1.2 "Certain things I still don't want to accept like not being able to walk. I accept it but I don't accept it." (17-year-old American female)
1.3 "I am glad that I am taking medication because am living." (12-year-old Ugandan male)
1.4 I feel good (about my illness) because I'm at home ... with my friends and cousins and brothers and sisters and moms and dads and aunts and uncles. (9-year-old American female)
1.5 When my hamster died I kinda just like got a new one but I mean that's not really the way to go about it but I don't know. It kinda helped to get something - to change something to get it off your mind. (17-year-old American male)
1.6 "I feel like my illness is normal and I know I will soon be better ... most of the time I feel well." (17-year-old Ugandan female)
1.7 "My leisure time, I spend it in football, band. I drum and play trumpet. I speak with friends who will develop me. The ones who don't develop me ... each time never get someone who can't support you. Each time I need friends who can support me." (12-year-old Ugandan male)
1.8 I feel like it (sib and boyfriend have sibs with chronic illnesses) kinda makes us like stronger because it kind of gives us like something in common and like we constantly talk about it. (17-year-old American female sibling)
2. Resilience and contemplating one's own death inform each other
2.1 "It's not fun and every day you think you're not gonna wake up, but you just thank the Lord everyday that you are woke up and you try to have a good time. I've been getting more aware of things, how I'm going to react to them. Sometimes I'm bad at reacting to them, but over the years it gets better and better." (15-year-old American male)
2.2 "... to live a good life I have to pass this situation. I have to pass this moment." (15-year-old Haitian female)
2.3 "Am scared about death.... Sometimes people die badly, accidents, and others die when they don't know what killed them ... I fear death because I still have things to do." (13-year-old Ugandan male)
2.4 "... in my life, yeah I can (fear death) and have stigma, but I can somehow remove it because you see many people can't be what I am." (12-year-old Ugandan male)
2.5 "It's really small ... everyone knows everyone ... it's good when we have cases like my brother, everybody knows us so they like kinda came together...." (17-year-old American female sibling)
3. Spirituality and interpreting loss inform each other
3.1 "the funny thing is ... at the balloon launch, mom's balloon goes like *flop flop sound* and all over the place, it's like grandma stop I know it's her messin ... I went to take laundry in the bathroom, books are flying at me it's like 'ahhh stop it,' it was either the laundry basket or it was grandma I don't know ... my mom had her wedding ring and it's gone, we- I think my grandma has something to do with it.... And she hid it somewhere, that's what I think ... their spirit leaves their body and goes up in the sky, it becomes part of the stars, and this the brightest star in the sky I always think is my grandma." (13-year-old American male)
3.2 "I cried just a little bit because I knew he (grandfather) would be safe wherever he's going - like heaven." (12-year-old American female sibling)
3.3 "I feel like it's [heaven] like earth except everybody's there and like everybody's happy and everybody's like at peace." (14-year-old American female sibling)
4. Altruism and how loss is perceived inform each other
4.1 "Almost every day I feel tired because of my medicine but I don't act like it because I like to make people happy, I like to make people happy ... I like to joke around a lot." (15-year-old American male)
4.2 "Went to the funeral, but I forget what his (grandfather's) funeral was." [Conveyed good memories] "I always pray for him at night." (9-year-old American female)
4.3 "I don't like to talk about her (great-grandmother) because my grandma cries when I talk about her." (7-year-old American female)
4.4 "My great grandpa, one of my great aunts has passed away ... sometimes it's just as hard for you, even if you didn't really know them because it affects the people around you and that kinda affects how you feel ... it makes you upset." (17-year-old American male)
5. Loss and experiencing growth are related
5.1 "I learned a lot of things in my life that I can't even tell you. Like there's so much in brains get confused. There's a big journey in life ... I've been getting more aware of things and how I'm going to react to them.... Sometimes I'm bad at reacting to them but over the years I'm getting better and better ... [what kind of things have you learned?].... Probably be aware of surprises in your life." (15-year-old American male)
5.2 [Loss of normalcy] "I am fine, am even happier than other people." (12-year-old Ugandan male)
5.3 "... (my preacher) ... saved me and what I feel like it is, is I feel like it just kinda like strengthens that relationship between you and God and it kinda just like, it makes you feel like you can become a better person...." (17-year-old American female sibling)
5.4 [Loss of normalcy] "in a positive way. I kinda had to grow up faster ... I think it made me a stronger person ... I've become more determined to get stuff done ... the positives definitely outweigh the negatives." (17-year-old American male)

(Continued)

Table 2. (Continued.)

Major process
6. Loss and contemplating one's own death inform each other
6.1 "My father died when I was five years old, many people came and he was buried in the soil. People were crying and I also started crying but my Aunt took me away at that time. He dies because of sickness, of HIV. We used to go together to the hospital to get the same medicine." (8-year-old Ugandan female)
6.2 "I don't know the name of the disease but what I know is that, it normally throws her down and at times throws them in fire, biting of tongue and all her body has scars. Her mother also have the same condition." (18-year-old Ugandan female)
6.3 "The funeral was hard, like especially since I've just gotten out of the hospital, I was seeing a lot of people that I hadn't really seen in a while so they kind of were like comforting to me because I had been sick and everything and just seeing those people was nice but like the funeral was really difficult for me." (17-year-old American male)
6.4 "Have you seen things in the hospital that are bad or scary?" "Like children that he's seen die, he's scared of ... afraid of sleeping with any person that is sick because he's afraid that he'll die the next day ... afraid of closing his eyes because when he closes his eyes he sees a picture of the dead person." (15-year-old Haitian male)
6.5 "He can see a kid die in front of him and he just stand in front of them staring at them. She has to carry him and go outside. He doesn't scare at all. He likes to look at the dead people. "Have you seen other kids die in the hospital?" Yes "And what does that make you think about?" Mom: He says for God to hide him and then he doesn't say anything. (6-year-old Haitian male)
6.6 "Says she just when she saw that one die, she just scared, she's just scared." (9-year-old Haitian female sibling)
7. Altruism and contemplating one's own death are related
7.1 "Pray for those that are still living not to pass the way the kid that died passed." (15-year-old Haitian male)
7.2 "there's like a new patient, a new little boy that has the same problem, so the first time when he comes he cries a lot and he talks to them and he talks to them and says I was like this too when I first came here I understand your situation so do not get discouraged, I was like this. I understand what you're going through." (14-year-old Haitian male)
7.3 "I spend my nice day with fellow youth, when I have come to (town) to teaching them about HIV and how we can prevent ourselves. Because when I teach the youth, it gives me hope that at least when we reach 2020. We shall have reduced the number of children who get HIV and those who take drugs, the virus is at zero, that already what we want we have reached it. What we call 90-90 ... 95/95 has reached." (16-year-old Ugandan male)
7.4 "I try to spend a lot more time with him than we used to and when I do I'm not as, I'm a lot more nice to him than I was, like I don't constantly like try to fight with him or everything else that we used to do I kinda just try to, you know, understand a little bit more." (17-year-old American female sibling)
8. Spirituality and contemplating one's death inform each other
8.1 "Have you seen other kids die?" Yes 'Where?' Here. "What was that experience like for you? "Like hard and scared and hard and frightening... So when I see that kid die in front of me, I pray to God to get me out of the hospital so I can get healed." (14-year-old Haitian male)
8.2 "Was anything ever bad or scary in the hospital?" "Zombie ... when it was dark." (5-year-old Haitian male)
8.3 "That's why I was scared to die, because you don't really know what's gonna happen ... I mean they're descriptions of it but no one's ever like been able- you can't go and come back to tell people. Maybe their spirit [feels something] but their body doesn't feel pain or anything. They might be happy that they're not suffering anymore but I don't think they feel anything." (17-year-old American male)
8.4 "I'm scared about demons at the hospital, has seen demons at the hospital, tells them to go away and they listen." (5-year-old Haitian female)

grandmother was still around: "My mom had her wedding ring ... it's gone. I think my grandma has something to do with it and she hid it somewhere ... that's what I think." In fact, whenever something unusual occurred in his home, the participant was quick to believe that his grandmother was somehow involved: "The funny thing is [at] the balloon launch, mom's balloon goes like [flop, flop sound] and all over the place, it's like, "grandma stop! I know it's her messin'!" Even if there was another potential reason for the occurrence, he appeared to be comforted by the possibility that it was his grandmother.

Spirituality and anticipating death

Data showed that the process between spirituality and anticipating death was bidirectional. Spirituality influenced how a 9-year-old Haitian boy anticipated death when asked to explain what it was like to see another child die. He admitted that seeing the deceased child was "... hard and frightening," but he used his belief in prayer to help: "So when I see that kid die in front of me, I pray to God to get me out of the hospital so I can get healed." Several Haitian participants feared negative manifestations of death such as

"zombies when it's dark" (5-year-old Haitian male) and "demons at the hospital" (5-year-old Haitian female). Responding to a question about having seen demons at the hospital, the girl said she "tells them to go away and they listen." Consideration about spirituality's meaning within the context of death was described by a 17-year-old American male who said he was "scared to die because you don't really know what is going to happen." He expanded on his uncertainty when he said, "I mean there are descriptions of it but no one's ever been able ... you can't go and come back to tell people."

Process of loss and anticipated death

Data showed that previous loss affected how the children anticipated death. Concern that their illness could result in death was evident for many children who described a "fear" of dying but was compounded for several Ugandan children whose parents struggled with or died from the same illness they also had. An 18-year-old Ugandan female described her mother's epilepsy: "... it normally throws her down and at times throws them in fire, biting of tongue and all her body has scars." She explained

that “[grandmother] also has the same condition” making it multigenerational, and, for this participant, “this sickness attacks me every day.”

The stories from the Ugandan children indicated that they had more exposure to death than did the American and Haitian children. For example, a 16-year-old Ugandan male said, “my dad died ... many people have died...,” while another informed the interviewer that, “yes, even just today my relative has gone for burial – someone has died.” While some of the Ugandan children were not necessarily bothered by witnessing the death of someone else, others were, similar to the Haitian children reported previously. A 13-year-old Ugandan male said that when he “was next to my dead auntie, it didn’t feel nice. I felt like it could be me dead.” In another case, a 10-year-old Ugandan female described seeing another child who had hung herself and speculated on a possible reason why. “Maybe the father had annoyed her and she went up, when going to school, climbed up on the children’s bed and onto the stool.” However, after considering the child’s death, the participant said they “felt bad” and decided “let me take medication because I also don’t take medicine, I can also die.” Participants reflected on their own behaviors after seeing the consequences of actions that could lead to death.

Discussion

We present results of a multinational grounded theory study of how children understand dying and death, an identified global palliative care research priority (Downing et al. 2015). Our results deepen the understanding of how children think about dying and death in the context of serious illness, whether their own, or a family member’s. The children in the present study were very aware of death, had experience with dying and death, and were able to conceptualize dying, death, and, in some cases, an afterlife, within the vocabulary they had to express themselves. While some providers are hesitant to address dying and death topics directly with children, our results suggest that children are already aware of these issues at some level (Cotton et al. 2014; Friebert et al. 2020). The question then shifts to *how* rather than *whether* to talk with children about dying and death. Curricula and frameworks are available to guide providers with these conversations (American Academy of Pediatrics n.d.; Dalton et al. 2019; Stein et al. 2019).

Our findings offer guidance about children’s concerns related to dying and death. The topic of loss, both of normalcy and of relationships, was a significant theme, deserving clinical attention. Our results suggest a proactive approach because it may bolster children’s resiliency and thus their ability to cope and ultimately grieve well. We refer to bidirectional relationships when the categories influence each other. The bidirectional relationships between loss and resiliency, altruism, and spirituality provide 3 potential topics from which to move toward a discussion of loss and its meaning for a child. The data show that some children express their understanding of dying and death through altruism, such as with spontaneous peer-to-peer support, thus showing the value of creating and/or expanding peer programs.

Our findings also underscore the presence and importance of children’s rich spiritual lives (Coles 1991). While spirituality is frequently seen as a positive resource for coping, children also experience spiritual struggles which include troubling beliefs or questions and dissonance between beliefs and experience (Cotton et al. 2013; Grossoehme et al. 2016). Children may not spontaneously disclose these thoughts to providers but may be able to respond openly and honestly in their own ways to adults who

inquire (Cotton et al. 2012; Pendleton et al. 2002; Schreiner et al. 2020). Thus, clinicians should be encouraged to explore these crucial dimensions with seriously ill children to bring their full selves into resilience and healing.

In addition to clinical implications for proactively addressing loss and grief, as well as attending to children’s rich spiritual lives, the results inform engaging children with serious illness and siblings so that they can collaborate in decision-making about both their treatment and their end of life. Palliative care and hospice programs should be designed – and care delivered – with cultural humility, embracing differences in understanding between individuals with diverse backgrounds. The results also inform anticipatory grief support for children undergoing treatment for serious illness and their siblings. Awareness of the concepts that they understand and how they construct meaning and grow (resilience, altruism, and spirituality) can enable children to be supported with appropriate strategies highlighting their strengths while honoring the grief and loss that they experience.

National guidelines call for the competent integration of cultural and spiritual issues for quality hospice and palliative care (National Consensus Project for Quality Palliative Care 2018). Our data present the voices of children, and while their expressions may differ from adult descriptions of the experience, we see that issues of loss (normalcy and relationships), resiliency, altruism, and spirituality are not that different from how other age groups anticipate death.

This study has the following limitations. One aim of this study was to give children a preliminary opportunity to contribute their voice to the problem of serious illness in their native languages and with the aid of interpreters. The investigators’ goal was to articulate a baseline understanding of the major issues the children were affected by or concerned about. Unfortunately, the limited sample size did not allow in-depth consideration of cultural differences. Further research with a larger and culturally stratified sample would enable a deeper understanding of cultural diversity and further refine this conceptual model. There was a significant delay between the data collection and completion of the analysis due to the logistics of a multinational partnership, data translation, and the COVID-19 pandemic. The sample size in each setting was relatively low, and siblings of hospitalized children in Haiti or Uganda were not available. Despite the interpreters’ best efforts, differences in linguistic structure, vocabulary, and culture may have affected analysis. A deeper exploration of ways in which resilience is experienced or expressed across cultures was beyond the scope of this study; however, those differences may be present. Finally, the majority of participants were Christians. Further research with greater religious and spiritual diversity would deepen understanding of how children understand dying and death. Nevertheless, important conclusions may be drawn. We suspect that some children may exhibit early signs of post-traumatic growth, but because this sample was actively involved in treatment, it may be too soon to assess. Additional research with survivorship may be warranted to fully explore post-traumatic growth for seriously ill children. Extending this exploratory study will increase understanding of the extent to which these themes are culturally bound or more universal. While this study does not permit specific practice recommendations regarding how to talk with children from diverse ages and backgrounds, it does support that, even at very young ages, children understand dying and death and highlights the importance of creating space for their questions. It is important to assess the child’s cultural context and to reinforce the need for cultural humility when training providers to maximize equitable care.

Further research about altruism, resilience, and spirituality across cultures may enhance culturally competent PPC.

Supplementary material. The supplementary material for this article can be found at <https://doi.org/10.1017/S1478951523000287>.

Acknowledgments. The authors gratefully acknowledge the participation of the children and their parents who agreed for them to be interviewed; Kristine Allmendinger-Goertz, Collins Ankunda, Jennifer Deuble, Judith Ellis, Zachary Fryda, Liz Grant, Gabriel Gue, Rachel Jenkins, Ruth Kemigisha, Priscilla Lebu, Mhoira Leng, Liz Nabirye, Ruth Nakayiwa, Liz Namukwaya, Juliet Namyeso, and Valerie Shaner; and the team at the African Palliative Care Research Network meeting at the 2013 African Palliative Care Association conference.

Funding. This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Conflicts of interest. None of the authors has any conflict of interest to disclose.

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