Journal of Pediatric Nursing 47 (2019) 92–99

Contents lists available at ScienceDirect

Journal of Pediatric Nursing

journal homepage: www.pediatricnursing.org

Thematic Analysis of Interprofessional Provider Perceptions of Pediatric Death☆

Stephanie Kukora, MD [a,b,*], Patricia Keefer, MD [c,d], Kenneth Pituch, MD [d], Janice Firn, PhD [b,e]

[a] University of Michigan Division of Neonatal-Perinatal Medicine, Department of Pediatrics, Ann Arbor, United States of America
[b] Center for Bioethics and Social Sciences in Medicine, University of Michigan, Ann Arbor, MI, United States of America
[c] Division of Geriatric and Palliative Medicine, Department of Internal Medicine, University of Michigan, Ann Arbor, MI, United States of America
[d] Stepping Stones Pediatric Palliative Care Program, University of Michigan Department of Pediatrics, Ann Arbor, MI, United States of America
[e] Department of Learning Health Sciences, Division of Professional Education, University of Michigan Medical School, Ann Arbor, MI, United States of America

ARTICLE INFO

Article history:
Received 22 August 2018
Revised 30 April 2019
Accepted 3 May 2019

Keywords:
Pediatric end-of-life
Neonatal end-of-life
Perceptions of death
Palliative care
Parent presence

ABSTRACT

Purpose: Though provider and patient perceptions of death are characterized in the adult population literature, there is limited information related to providers' perceptions in pediatric and neonatal patients. The purpose of this study was to better understand how interprofessional care team members perceive and experience neonatal and pediatric end-of-life situations.
Design and methods: This survey questionnaire was administered to interprofessional providers following their participation in an institutional workshop, as part of an ongoing institutional effort to improve end-of-life experiences for patients/family and providers. Interprofessional care providers completed an electronic survey consisting of closed-ended and one open-ended question to elicit their perceptions of their participation in end of life care for a recent neonatal/pediatric patient in the period before the child's death.
Results: The qualitative analysis of 306 free-text responses commenting on the deaths of 138 patients, contained within 880 completed mixed-method surveys, is described. Thematic analysis of the free text discovered three primary themes from the data: favorable aspects of the death experience, unfavorable aspects of the experience, and combined favorable and unfavorable aspects. Four subthemes contributed to the themes; namely, language, parental presence, trust/rapport in provider relationships and inclusion in decision-making, communication, and culture.
Conclusions: Multiple factors contribute to how interprofessional care providers perceive end-of-life care experiences for neonatal/pediatric patients. The same death may be perceived differently by different providers.
Practice implications: Understanding favorable and unfavorable aspects of providing end-of-life care will support strategies to provide resources, education and support to facilitate coping and resiliency in care providers.

Background

Although provider and patient perceptions of factors impacting the experience of a death have been well studied in adult patients, literature on provider perceptions in the pediatric and neonatal population is limited. In the adult population, perspectives from patients (Bingley et al., 2006; Chapple, Evans, McPherson, & Payne, 2011; Granda-Cameron & Houldin, 2012; Gott, Small, Barnes, Payne, & Seamark, 2008; Horne, Seymour, & Payne, 2012; Langley-Evans & Payne, 1997; Munn et al., 2008; Reinke, Uman, Udris, Moss, & Au, 2013; Small et al., 2009), their families (Chapple et al., 2011), and their providers (Arnold, Lloyd, & von Gunten, 2016; Black, 2005; Cipolletta & Oprandi, 2014; Jackson et al., 2005; Munn et al., 2008; Payne, Langley-Evans, & Hillier, 1996; Tenzek & Depner, 2017) have been characterized. Provider studies have focused on generalized values about death and death anxiety more than appraisals of the quality of specific deaths (Low & Payne, 1996; Peters et al., 2013a; Peters et al., 2013b).

Though some overarching themes have emerged regarding which aspects of end-of-life are viewed favorably or unfavorably, these studies note variability in reported perceptions, making it difficult to define specific aspects of a positive or negative death experience to guide clinical care in these contexts. This variability may arise from differences in the end-of-life situations investigated, including the environment (Kornfeld, 1977), disease type, patient population, as well as type of study, and timing of assessment before death (or after, recalled by family members and providers). Differences have also been noted between reported perceptions of patients compared to their families and

Abbreviations: ECMO, extracorporeal membrane oxygenation; PICU, pediatric intensive care unit; PCTU, pediatric cardiothoracic unit; NICU, neonatal intensive care unit; CES, children's emergency services; NEC, necrotizing enterocolitis.

☆ Clinical trial registration: None.

* Corresponding author at: Division of Neonatal-Perinatal Medicine, Department of Pediatrics, Mott Children's Hospital, University of Michigan Medical Center, 8-621 C&W Mott Hospital, 1540 E. Hospital Drive, SPC 4254, Ann Arbor, MI 48109-4254, United States of America.
E-mail address: skukora@med.umich.edu (S. Kukora).

https://doi.org/10.1016/j.pedn.2019.05.002
0882-5963/

healthcare providers. Likewise, disparate death perceptions have been identified between healthcare providers for adult patients in different disciplines, which may relate to clinical experiences with death in diverse contexts, as well as the contribution of personality type in selecting a particular profession or specialty (Payne, Dean, & Kalus, 1998).

In the pediatric and neonatal population in all types of health care settings, nearly 33,000 infants and children die annually in the US (Murphy, Xu, Kochanek, Curtin, & Arias, 2017), yet only limited literature exists about perceptions of death in these patients (Andresen, Seecharan, & Toce, 2004; Brooten et al., 2013; Davies et al., 1996; Hechler et al., 2008; Ito et al., 2015; Kreicbergs, Valdimarsdóttir, Onelöv, Henter, & Steineck, 2004; Lee & Dupree, 2008; Yam, Rossiter, & Cheung, 2001). Although the majority of pediatric and neonatal deaths occur in a hospital setting with end-of-life care administered by interprofessional providers (Feudtner et al., 2011), extant literature has largely targeted only family and patient perceptions (Brooten et al., 2013; Hechler et al., 2008; Kreicbergs et al., 2004). From the studies exploring provider perceptions, the evidence suggests staff emotional responses are influenced by the perceived quality of end-of-life care provided (Davies et al., 1996; Ito et al., 2015; Lee & Dupree, 2008; Yam et al., 2001) and providers' perceptions differ according to role (Andresen et al., 2004). These studies are limited to nurse and physician experiences with end of life care, leaving perspectives of other care team members, including respiratory therapists, social workers, and spiritual care providers, largely unknown.

Witnessing deaths in neonatal and pediatric patients is emotionally and ethically challenging (Kukora, Laventhal, Keefer, & Firn, 2018; Robins, Meltzer, & Zelikovsky, 2009), and can result in provider distress and grief (Davies et al., 1996; Lee & Dupree, 2008; Yam et al., 2001). Additional understanding of how interprofessional care team members experience end-of-life situations may help reduce burnout and compassion fatigue (Meadors & Lamson, 2008; Sundin-Huard & Fahy, 1999; Weintraub, Geithner, Stroustrup, & Waldman, 2016), as well as encourage coping and improved provision of future patient care (Kukora et al., 2018; Wallace, Lemaire, & Ghali, 2009). Likewise, better understanding of the providers' perceptions of death in these contexts can inform their future care when experiencing the stress of caring for dying infants and children. To address this gap, we sought to characterize interprofessional providers' perceptions of death to ascertain which features of end-of-life care they consider favorable or unfavorable, when given the option to share thoughts/comments/questions following their experience with a neonatal or pediatric patient for whom they provided direct care at the time of death.

The purpose of this project was to investigate how interprofessional care team members experience neonatal and pediatric end-of-life situations. Increased understanding and knowledge of interprofessionals' experiences in this area could inform the development of strategies and resources to support or improve coping skills and reduce burn out and compassion fatigue among providers.

Methods

An investigator-developed survey was administered to interprofessional care providers at a Midwestern academic children's hospital between October 2014 and May of 2016 as part of ongoing institutional improvement initiatives. The anonymous survey data was determined to be IRB exempt in conjunction with ongoing institutional quality improvement in provision of end-of-life care. Data were analyzed according to a constructionist thematic analysis of the free test responses to the open-ended question on the survey.

Survey

An electronic survey was developed by members of our institutional Pediatric Palliative Care Program, and reviewed for face and content validity by other Pediatric Palliative Care providers not involved in the study, as well as a focus group of physicians and nurses. Subsequently, the survey was piloted for feasibility and reliability (Del Greco, Walop, & McCarthy, 1987). No changes were made following a successful pilot. Specifically, the survey was developed to explore the perceptions of participants that had attended the interprofessional workshop and whether is affected the provision of care. The survey contained seventeen quantitative questions formatted in a 5-point Likert scale (for example: "To what extent do you agree or disagree with the following statements: The patient's death went as well as could be expected. (1) Strongly Disagree to (5) Strongly Agree") and one qualitative free-text response. The results of the quantitative portion are reported elsewhere (Pituch, Halsey, Keefer, & Azim, 2016). Demographic and situational data collected included details on case, type of death, and respondents' role, and past experience in providing end-of-life care. Respondents' names were not queried, and though respondents were asked about their roles, typically there were more than one of each provider role involved in the 24 h of care preceding the death. Additionally, other than provider role, all identifiable references to the deceased patients, their families, and the respondents themselves were removed from the responses prior to analysis, further ensuring anonymity. This qualitative analysis focuses on the final survey question, an optional, free-text comment question requesting that respondents "Please feel free to share thoughts, comments or questions about your experience surrounding the patient's death or about this survey."

Recruitment and data collection

Providers ($n = 2701$) identified via the electronic medical record as participating in providing care or authoring documentation for a patient less than 18 years of age within the 24-h period leading up to the patient's death were contacted for participation in the survey and asked to respond to the survey questions based on their experience with that specific patient's death, rather than their experience of patient deaths in general. Providers caring for more than one infant/child who died during the time period were able to complete the survey for each end-of-life experience in which they participated. The survey was e-mailed via Qualtrics (Qualtrics, 2016) within one week of the patient's death. Surveys were distributed following all 170 neonatal and pediatric patients' deaths occurring at our hospital during the study period. Surveys completed by different providers but regarding the same patient death were linked by patient; this allowed comparison of these responses describing the same clinical scenario, to elucidate whether perceptions of an end-of-life situation differed between care team members.

Data analysis

De-identified, free-text responses were imported into Microsoft Excel (2016) and descriptive statistics were completed. Free-text responses ranged from one to nine sentences in length, with a median length of four to five sentences. Constructionist thematic analysis of the data was conducted utilizing Braun and Clarke's approach (Braun & Clarke, 2006). We chose thematic analysis because it allows for identification, analysis and reporting of patterns (themes) within data, and facilitates organization and interpretation of different facets of the phenomenon being studied (Boyatzis, 1998). In thematic analysis, codes are used to capture a single idea within a selected segment of data (Braun & Clarke, 2006). Themes are formed when codes are combined and organized around a central concept, capturing a recurrent pattern throughout the dataset (Braun & Clarke, 2006). Rather than using theoretical or thematic saturation, themes are considered robust in thematic analysis when they are distinct and coherent and cohesive in relation to the coded extracts and the entire data set (Braun & Clarke, 2006; O'Reilly & Parker, 2013). Dedoose software (Dedoose, 2016) was utilized to organize data and improve transparency and credibility of the

analysis via a systematic and comprehensive audit-trail (Fielding & Lee, 1998; Sinkovics & Alfoldi, 2012). Thematic analysis was conducted on both semantic and latent levels (Braun & Clarke, 2006). In a semantic approach, the analyst is only looking at what the respondent has written; themes are identified within the explicit or surface meanings of the data, whereas in a latent approach, the analyst examines the underlying ideas, assumptions, and conceptualizations that contribute to shaping the semantic content of the data (Braun & Clarke, 2006). With a latent approach, theme development is inherently constructionist and involves interpretative work (Braun & Clarke, 2006). Codes and themes were identified and refined by the primary investigator who read and re-read respondent comments. Responses were independently read and coded by another member of the evaluation team; ambiguities and inconsistencies were resolved through discussion (Table 1). As thematic analysis is an active process that inexorably and unavoidably bears the analysts' experiences and perspectives, throughout coding and theme development, the group used critical reflection to challenge their assumptions and interpretations in an effort to reduce bias (Braun & Clarke, 2006).

Results

There were 306 (35%) free-text responses in 880 completed surveys (33% total response rate), regarding the deaths of 138 neonatal and pediatric patients (81% of the 170 in-hospital pediatric and neonatal deaths that occurred). The patient deaths represented occurred in a variety of hospital settings, including the Pediatric Intensive Care Unit, Children's Emergency Services, the Pediatric Cardiothoracic Unit, inpatient Hematology and Oncology, the Operating Room, the Neonatal Evaluation, Stabilization, and Treatment area, the Neonatal Intensive Care Unit, and Labor and Delivery (Table 2). Interprofessional care team members from diverse specialties and broad range of experience levels completed surveys, including Nurses, Physicians, Respiratory Therapists, Physician Assistants/Nurse Practitioners, Social Workers, Spiritual Care Providers, and others (i.e. Child Life, Extracorporeal Membrane Oxygenation (ECMO) technician) (Table 2). The majority of respondents were nurses and physicians (66%). Of the 306 free text responses, 136 (44%) of provided comments about the perceived quality of the death. These free responses described 94 individual patient deaths, with 28 deaths receiving comments from two respondents and five deaths receiving comments from three. Of the 94 patient deaths, 31 were unexpected and involved attempts at cardiopulmonary resuscitation; 41 of the 136 comments reflected on these deaths. The remaining 63 deaths occurred after planned non-escalation or withdrawal of life-sustaining therapies. These deaths were described in 95 of the 136 comments.

Table 1
Definitions arising from the data.*

Favorable aspects of death	Positive tone or reflections, and/or approval pertaining to the manner, situation, environment, or perception of the neonatal or pediatric patient death.
Unfavorable aspects of death	Negative tone or reflections, and/or disapproval pertaining to the manner, situation, environment, or perception of the neonatal or pediatric patient death.
Joint Favorable and unfavorable	Both positive and negative tone or reflections, and/or both approval and disapproval pertaining to the manner, situation, environment, or perception of the neonatal or pediatric patient death.
Language	Specific terms used by respondents to communicate favorable or unfavorable aspects of the manner, situation, or environment of the patient's death.
Parent presence	Specific mention of parents being present or not present at the time of the patient's death.
Relationship quality	Trust/Rapport: Specific mention of the trust or rapport between the provider team and patient/family and its impact on the patient's death. Shared Decision-Making: Specific mention of discussion regarding prognosis or end-of-life decision-making between the provider team and the patient/family impacting the patient's death. Communication: Specific mention of communication within or between providers on the team and patient/family members impacting the patient's death.
Cultural considerations	Specific mention of provider team efforts to individualize the care provided to adhere to a patient's/family's cultural practices and customs surrounding death and dying.

* Definitions determined via discussion among authors. Braun and Clarke (2006) support authors' creation of thematic definitions from the data.

Table 2
Units in which pediatric and neonatal deaths occurred and roles of respondents.

Units of responses	All surveys (n = 880)		All free-text (n = 306)		Described death free-text (n = 136)	
Pediatric intensive care unit	333	38%	120	39%	56	41%
Children's emergency services	15	2%	4	1%	0	0%
Pediatric cardiothoracic unit	196	22%	66	22%	29	21%
Hematology and oncology	14	2%	4	1%	3	2%
Operating room	17	2%	4	1%	3	2%
Neonatal evaluation, stabilization, and treatment	16	2%	6	2%	4	3%
Neonatal intensive care unit	265	30%	93	30%	38	28%
Labor and delivery	24	3%	9	3%	3	2%
Respondent role:	All surveys (n = 880)		All free-text (n = 306)		Described death free-text (n = 136)	
Nurse	210	24%	101	33%	53	39%
Physician	309	35%	88	29%	37	27%
Respiratory therapist	120	14%	31	10%	14	10%
Physician assistant/Nurse practitioner	32	4%	14	5%	5	4%
Social worker	79	9%	25	8%	17	13%
Spiritual care provider	56	6%	12	4%	6	4%
Other (i.e. Child Life, ECMO* technician)	74	8%	35	11%	4	3%

* Extracorporeal membrane oxygenation.

Favorable and unfavorable language

The majority (86, 63%) of free-text responses described aspects of the death favorably. Common terms describing death favorably included "peaceful," "comfortable," "quiet," "with dignity," and "going smoothly." These words were utilized by providers in a variety of disciplines in describing deaths of different patients. "*It went smoothly and with dignity*."—Respiratory Therapist, patient 246. "*It's comforting to know we gave her peace and comfort in her final hours.*"—Bedside Nurse, patient 173. The vast majority of deaths described favorably with these terms were following planned withdrawal or non-escalation of care. "Peaceful" and "with dignity" often described the patient, while "quiet" described the environment, and "going smoothly" described coordination of the care provided. Comfort/comfortable occurred with the highest frequency in responses and had many uses; it often described the patient or family, but occasionally respondents used it to describe their own comfort with the situation and or their role in comforting families.

Conversely, 59 (43%) responses described negative aspects of patient deaths. Many, respondents described unfavorable end-of-life scenarios as "messy," "clumsy," "chaotic" and "uncomfortable". "*One thing that was difficult, though, was the sheer number of unoccupied staff in and around the patient's room throughout the code and transfer to PICU [Pediatric Intensive Care Unit]; this contributed to some of the confusion I saw and made for a somewhat chaotic and noisy environment for the family.*" —Spiritual Care, patient 118. "*I was completely blindsided to the new plan to prepare to withdraw support and unsure of how prepared family was for this news…The whole thing felt a little rushed and odd…Parents were shocked and confused…Death of an innocent infant is never comfortable this time it just felt sort of clumsy.*" —Bedside Nurse, patient 161. Three situations contributed to unfavorable responses to the patient's

death: challenging environment, unexpected deaths, prolonged deaths. Respondents who described the environment (Kornfeld, 1977) unfavorably did so both in terms of the negative impact of the circumstances on the family and themselves, and on their ability to provide end-of-life care effectively. Comments reflecting on the unexpected nature of the death occurred for deaths of both previously healthy children and children who succumbed to a prolonged illness sooner than anticipated. Many of the responses that described unexpected deaths as unfavorable described code situations. For the deaths following withdrawn therapies that were described as unfavorable, respondents perceived that the provision of intensive therapies in these cases had been prolonged and burdensome, and that this had negatively impacted the end-of-life experience.

Parent presence

Parental presence or absence at the time of the death was noted by many of the respondents as being impactful on their perception of the death. Respondents viewed having the parent(s) at the bedside and interactive with the patient as valuable for most deaths, and often utilized favorable terms (listed above) when describing parent/child interactions in end-of-life care. "*I think it was extremely valuable that parents were able to stay at bedside throughout patient's resuscitation in CES [Children's Emergency Services], because they saw how difficult it was and were later able to make a decision to make patient comfort care after admission.*"—Social Worker, patient 125. Some comments reflected personal satisfaction as a provider in facilitating family participation in caring for the patient in these scenarios. Some providers commented that witnessing aggressive interventions seemed to influence parents' decisions to discontinue treatment and change goals of care to comfort, thereby reducing prolonged, burdensome care. Parental presence was not always described positively, however. Some respondents reported concern that witnessing the patient's death was traumatic for the patient's family, and suggested that it would have been preferable had the family not observed it. "*The reason I would say the patient's death did not go as well as planned would be because the patient was transported here after coding…. Her parents walked in to see us doing chest compressions on her and I am sure they will never be able to forget that sight.*" —Bedside Nurse, patient 211. Likewise, some comments noted that parent presence negatively affected providers in some end-of-life situations. "*I understand that this facility strives for family centered care; however, I did not agree with having the parents in the room during the activity of coding and attempting to get her on ECMO [Extracorporeal Membrane Oxygenation]. It was A LOT to handle for the parents and the caregivers.*"—Operating Room Charge Nurse, patient 130. While there were differences of opinion on parental presence, parental absence was always viewed negatively by providers. *"My main regret is that the family wasn't there for the patient's death. They were an hour away, and continuing a resuscitation for that long without real potential for success did not seem appropriate, but in retrospect I wish they had been contacted overnight alerting them that the patient's condition was worse, and that they may want to come to the hospital."* —Attending Physician, patient 187. In addition to the perceived effects on the patient and the family, comments denoted additional stress for the individual providing care according to their role. The parents' absence was also sometimes felt to contribute to prolongation of the child's inevitable death. No respondents expressed appreciation that a patient's parents were absent. Barriers to a family's ability to be present and interact with their dying child, such as police presence in cases of non-accidental trauma, were also reported unfavorably. *"Non-accidental traumas that result in death are hard…In this case, the detectives at bedside heightened the anxiety and discomfort with what we needed to do. The initial instructions from the primary detective was that the child could NOT be held when removed from life support. This was very disturbing and not conducive to care we give. After much work by the bedside RN permission was given for him to be held. The family was not allowed any privacy or time alone with the deceased child. The detectives stayed at the bedside while the parents held and said goodbye."* —Respiratory Therapist, patient 168.

Relationship quality

Relationship quality consisted of three subthemes: perceived quality of trust/rapport, shared decision-making, and communication, both among members of the care provider team as well as between the team and family. These strongly influenced providers' perceptions of neonatal and pediatric death. Multiple providers noted how an established patient-provider relationship facilitated provision of care and end-of-life goals discussion. *"It is difficult to be the best support for a family when you do not have a rapport developed with the family. I was glad for the family that on the actual time of her passing, a primary team member was available to take her. It's better for the family."* —Bedside Nurse, patient 156. Likewise, several respondents described that a lack of relationship impeded the ability of the care team to perform functions related to their role, including disclosing bad news, engaging in shared decision-making, and comforting patients and their families. *"Despite having been involved in many end of life discussions over the course of my fellowship, this was one of the most difficult situations I've been faced with. (Having to tell a family that I am meeting for the first time that their child is dead/dying)."* —Subspecialty Fellow, patient 155. Providers also reported perceptions that an established relationship with providers improved families' experiences with their child's death.

Mixed favorable and unfavorable

Favorable and unfavorable comments were identified in a number of responses, suggesting provider perceptions of neonatal and pediatric death form a continuum rather than an either/or response. Often, respondents would provide praise for the teamwork or actions of care provider team members, while noting that the circumstances of the death itself was sub-optimal. *"I feel that overall everything went well from all disciplines involved. However, there was a problem with bereavement trays. Apparently the family had reached their limit? How can this be? There stay was extended because they were donated their child's organs. There should be no "limit" on food or how we care for them!! This was unacceptable."*—ECMO (Extracorporeal Membrane Oxygenation) Technician, patient 146. "*Unexpected death following extubation of a ELBW [Extremely Low Birth Weight] preterm infant. Everyone on care team very strongly affected by this… NICU [Neonatal Intensive Care Unit] attending for the patient who was running the code was outstanding with the parents after the event, ensuring the timely pronunciation of death and allowing family time with their child.*"—Senior Resident, patient 243. Likewise, for the 32 deaths on which there were more than one respondent providing comments, perceptions of the death were not always aligned between respondents (Table 9). Similar perspectives were expressed by respondents of the same and diverse disciplines for some cases. "*Our team tried with everything we had to bring this child back to life. Unfortunately, he could not be brought back. The teamwork that was needed in this case was extraordinary. I am so proud to be part of the NICU [Neonatal Intensive Care] team.*" –Bedside Nurse, patient 217. "*Nursing staff did a tremendous job and appeared very emotionally impacted by this death.*" –Spiritual Care, patient 217. Often these comments reflected praise for members of the care team. For deaths in which the comments differed in regard to positive or negative perceptions, some seemed attributable to the professional's role in the death situation. "*I felt the patient suffered more than he needed to and it was traumatic for the parents…I feel we essentially suffocated the patient before we pulled the tube…Normally we ventilate the patient appropriately until we give MSO4 and then withdraw the tube at that time. It seems much kinder and gentler than the way this withdrawal was done.*" –Respiratory Therapist, patient 266. "*Baby's demise was quicker than expected once ventilator support was weaned down, it was family's wishes that their baby would not be agonal, and I feel like that was provided.*"–Nurse Practitioner, patient 266. For others

deaths, the disparate perceptions of providers of the same discipline reflected different personal views about death and their role in providing that patient's end-of-life care. "*The prognosis was already very poor. The parents were then given some sort of hope that she could be ok by making them travel hours down here from the UP. She was then taken to surgery where she coded, brought to ICU [Intensive Care Unit] where although they said she wouldn't survive, it was terrible to know they put her and her parents through going to surgery when they knew she wasn't going to live…I just wish she hadn't been brought down here when everyone knew she was more than certainly going to pass.*" –Bedside Nurse, patient 211. "*The team work was phenomenal. This patient received outstanding care and so did her parents.*" —Bedside Nurse, patient 211.

Cultural considerations

While considerable evidence exists that efforts to individualize the care provided to adhere to a patient's cultural practices and customs surrounding death and dying positively impacts the end-of-life experience (Fang, Sixsmith, Sinclair, & Horst, 2016), it was mentioned only once, *"This was also a difficult case due to a language barrier. Father spoke English but mother did not. Trying to comfort a parent through an interpreter is very difficult, I find"*—Social Worker, Patient 125. Whether culture was not emphasized by the respondents because they felt it was not influential to the death or because there were not specific challenges in accommodating patients' cultural practices is unclear.

Discussion

This survey included the opportunity for providers to respond to a single open-ended question designed to better understand how interprofessional care team members experience neonatal and pediatric end-of-life situations with the aim to reduce burn out and compassion fatigue. To our knowledge this is the first time interprofessional providers have had the opportunity to share their perceptions on the topic. The findings from respondents contributed to the growing body of evidence related to how participating in patients' end-of-life care affects interprofessional providers.

In particular, we learned that perceptions are influenced by factors such as contextual features of the death, parent presence or absence, and trust and rapport in the provider/patient relationship. We also noted that death perceptions were not always strictly favorable or unfavorable, but were mixed with elements of both reported by respondents, and that perceptions of the death of the same patient were variable among providers. This suggests that provider discipline, experience, and specific role in end-of-life care may shape how a neonatal or pediatric patient's death is perceived.

Respondents in our study described patients' deaths with similar language to what has been reported in other studies, particularly with the association of "peaceful" and "dignity" with positive perceptions. (Andresen et al., 2004; Epstein, 2008; Hemati et al., 2016; Ito et al., 2015; Meier et al., 2016; Payne et al., 1996) Conversely, they reported unexpected deaths and excessively drawn-out deaths as unfavorable, which is similar to findings in providers recalling deaths of adult patients. (DelVecchio Good et al., 2004; Jackson et al., 2005) This finding suggests that circumstances and timing contribute to perceptions, specifically that for death in neonatal and pediatric patients to be perceived favorably by providers, it should neither be fast and unexpected, nor prolonged with burdensome suffering. As previously has been reported (Davies et al., 1996; Koesel & Link, 2014; Payne et al., 1996), providers' descriptions of a death as favorable or unfavorable stem from both their identification with the patient and family, with how the end-of-life experience fits with their personal values, and their own experience with providing care to that patient. Perceptions of death have been noted to differ between provider role in studies of adult (Payne et al., 1998; Peters et al., 2013a, 2013b) and pediatric (Andresen et al., 2004; Epstein, 2008; Yam et al., 2001) end-of-life care. However, the prior studies have been limited to physicians and nurses, have a small sample size, or reflect generalized recollections of patients' deaths rather than specific experiences. We also observed that professional as well as specific role/tasks in providing end-of-life care impacted how the experience of the death of a neonatal or pediatric patient is perceived. In adult care providers, these differences in perception have been attributed to personal experiences gained from working in that profession or specialty, as well as personality differences that influence the decision to pursue a particular profession or specialty (Payne et al., 1998); we speculate that a similar combination of factors shape the differing perceptions between providers for neonatal and pediatric deaths. Unlike previous pediatric and neonatal studies (Andresen et al., 2004; Low & Payne, 1996; Yam et al., 2001), respondents in our survey rarely conflated their perception of their own personal ability to complete necessary tasks, such as pain management, with the overall quality of the death.

In addition to specific features about the manner in which the death occurred, respondents also noted the importance of interpersonal factors, such as parent presence. Parental presence at the child's bedside at the time of death was commented on by many respondents, typically favorably when the death was expected, though occasionally unfavorably when the death was unexpected and aggressive resuscitation had been employed. While parent presence being viewed favorably is consistent with the adult (Granda-Cameron & Houldin, 2012; Meier et al., 2016) and neonatal/pediatric (Garros, 2003; Welch, 2008) literature which suggests that having family at the bedside has a positive impact on a death experience, parent presence being viewed unfavorably in unexpected deaths with aggressive resuscitation differs from parents' perspectives that witnessing their child's resuscitation is beneficial and can be impactful on bereavement and closure (Shaw, Ritchie, & Adams, 2011). Parent absence and barriers to parents' interaction with their child were always perceived poorly, interestingly even in circumstances when there was suspicion that a parent was potentially responsible for harming the child. Similarly, trust and rapport in the relationship between the provider and patient/family was noted frequently by our respondents as being positively influential on the experience. The importance of trust with the therapeutic relationship has been well studied (Eden & Callister, 2010; Fins & Solomon, 2001; Rosenthal & Nolan, 2013; Valdez-Martinez, Noyes, & Bedolla, 2014), and is known to be particularly important in situations of uncertainty, complex decision-making, and high emotionality like end-of-life care, so it is not surprising that it was identified by providers in our study as playing a role in neonatal and pediatric end-of-life care.

Finally, we noted that culture sensitivity, although reported as important (Andresen et al., 2004; Hemati et al., 2016; Payne et al., 1996; Welch, 2008) was not a factor in our respondents' comments. Further investigation of the impact of patients'/families' cultural preferences on neonatal and pediatric death in the future is warranted.

Practice implications

Much of the existing literature on care providers has contributed to the widespread belief that death is either "good" or "bad" (Andresen et al., 2004; Garros, 2003; Gott et al., 2008; Ito et al., 2015; Koesel & Link, 2014; Low & Payne, 1996; Meier et al., 2016; Payne et al., 1996; Welch, 2008). Respondents in our study, however, often reported both elements they found favorable and elements they found unfavorable within the same comment. This suggested that providers' experiences around the deaths of neonatal and pediatric patients were nuanced. The impact of past experiences caring for dying patients on future care provision has been reported for diverse medical professionals (Barr, 2007; Black, 2005; Peters et al., 2013a, 2013b). Creating opportunities for reflection as an interprofessional group on the continuum of responses to a death may serve to foster coping and resilience (Kukora et al., 2018). Several studies have shown the benefits of team debriefing after challenging experiences, including positive impacts on teamwork,

end-of-life care, and provider stress (Govindan, Keefer, Sturza, & Malas, 2018). Identifying positive aspects in unfavorable death situations in the context of an interprofessional debrief session may prevent burnout and compassion fatigue in providers frequently caring for critically ill/dying neonatal and pediatric patients. Likewise, encouraging interprofessional discussion about areas for improvement in favorably perceived death situations could lead to development of strategies to optimize care provision in this context. Our finding that perceptions of the death varied between providers caring for the same patient further supports the practice of team debriefing. Sharing these experiences through debriefing may help providers to understand differing perspectives to aid in both managing grief around the recent death, improving future practice, and reducing burnout and compassion fatigue.

Strengths and limitations

Our survey is limited by the short nature of the free-text survey response, which does not provide opportunity for follow-up questions or probes, and makes it difficult to ascertain provider's perspectives in depth. It remains unclear whether unfavorable perceptions were due to unavoidable circumstances such as an unexpected death, undesirable environment, or unavoidable issues with parents. Though free-text responses are less lengthy than qualitative interviews, they identify important issues not asked directly by the close-ended survey and can inform future research (Garcia, Evans, & Reshaw, 2004; O'Cathain & Thomas, 2004). Variability in length and quality of the free-text responses provided opportunities for respondents to choose what they wished to discuss, as well as raise points that otherwise may not have been addressed. Though only a minority of respondents provided free text comments in our survey, this is not unusual (Garcia et al., 2004). Those providing comments are more likely to be articulate, have adequate time to complete the survey, or wish to express a negative or critical remark (Garcia et al., 2004). Conversely, respondents who struggle to express themselves in written form, who may have time constraints in completing the survey, or do not have a strong negative experience are less likely to comment (Garcia et al., 2004). These characteristics may have influenced the quality and quantity of the free-text responses in our survey. Follow-up studies, including in-depth interviews on these important issues are needed to further investigate opportunities to improve end-of-life care provision and its impact on providers rendering this care to dying infants and children.

An additional limitation is that our study was conducted at a single center and addressed individual neonatal and pediatric deaths, a relatively infrequent occurrence compared to death in adult populations. Rigor in qualitative research is centered on transferability to other settings rather than generalizability across populations, providing the potential that our results are applicable to other neonatal/pediatric situations and interprofessional care providers (O'Cathain & Thomas, 2004). Despite being a single-center study, our results are likely applicable to other institutions, given that deaths are universal to most pediatric hospital environments and frequently occur in an ICU setting.

There was overrepresentation of nurses and physicians in our responses relative to other interprofessional care providers. This is unsurprising as there are usually many providers in these roles involved in end-of-life care, whereas there are fewer other interprofessional providers, including respiratory care specialists, social workers, and spiritual care providers. The roles represented by respondents providing free-text comments were similar across units and to the demographics of all respondents to the survey, including those who did not provide a response to the free-text question. Unfortunately, the roles of providers who were sent a survey but declined to complete it are unknown. Additionally, as providers were able to complete a survey for each patient's death for which they provided end-of-life care, there is a possibility that some provider's views were overrepresented in our survey. Since respondents did not provide their names in the anonymous survey, our ability to identify whether the same provider completed the survey on multiple patients was limited.

Finally, 20 of the 306 respondents who gave free-text comments denied directly caring for the patient 24-h prior to death in another survey question. These comments were not removed from the data set, as they demonstrated substantive content and relevance to the research question; specific details about the patient/family or situation surrounding the death provided in their descriptions suggested they were familiar with the case and could offer reliable input.

Conclusion

Though neonatal and pediatric death is never desirable, specific characteristics of the patient's death and end-of-life care influence providers to view some neonatal or pediatric deaths more favorably than others. Gaining a better understanding of what providers perceive as positive aspects in unfavorable death situations and areas for improvement in those perceived favorably will contribute to a better understanding of the perceptions and experiences of interprofessional providers during end-of-life care for neonatal/pediatric patients and their families.

Funding source

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

Financial disclosure

The authors have no financial relationships relevant to this article to disclose.

Conflict of interest

The authors have no conflicts of interest to disclose.

Contributors' statement

Stephanie Kukora devised the project, developed the coding scheme and performed qualitative analysis on the survey free responses, wrote the initial draft, and revised the manuscript.

Patricia Keefer collected and de-identified the survey data, assisted in development of the qualitative coding scheme, and revised the manuscript.

Ken Pituch assisted with the design and implantation of the survey and revised the manuscript.

Janice Firn assisted in development of the qualitative coding scheme as well as with coding the data, and revised the manuscript.

Acknowledgments

We would like to thank Dr. James Azim and Melanie Halsey for creation and distribution of the survey.

References

Andresen, E. M., Seecharan, G. A., & Toce, S. S. (2004). Provider perceptions of child deaths. *Archives of Pediatrics & Adolescent Medicine*, *158*(5), 430. https://doi.org/10.1001/archpedi.158.5.430.

Arnold, B. L., Lloyd, L. S., & von Gunten, C. F. (2016). Physicians' reflections on death and dying on completion of a palliative medicine fellowship. *Journal of Pain and Symptom Management*, *51*(3), 633–639. https://doi.org/10.1016/j.jpainsymman.2015.09.006.

Barr, P. (2007). Relationship of neonatologists' end-of-life decisions to their personal fear of death. *Archives of Disease in Childhood. Fetal and Neonatal Edition*, *92*(2), F104–F107. https://doi.org/10.1136/adc.2006.094151.

Bingley, A. F., McDermott, E., Thomas, C., Payne, S., Seymour, J. E., & Clark, D. (2006). Making sense of dying: A review of narratives written since 1950 by people facing death from cancer and other diseases. *Palliative Medicine*, *20*(3), 183–195.

Black, K. (2005). Social workers' personal death attitudes, experiences, and advance directive communication behavior. *Journal of Social Work in End-of-Life & Palliative Care*, *1*(3), 21–35. https://doi.org/10.1300/J457v01n03_03.

Boyatzis, R. (1998). *Transforming qualitative information: Thematic analysis and code development.* London: Sage.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa.

Brooten, D., Youngblut, J. M., Seagrave, L., Caicedo, C., Hawthorne, D., Hidalgo, I., & Roche, R. (2013). Parent's perceptions of health care providers actions around child ICU death: What helped, what did not. *American Journal of Hospice and Palliative Medicine*, *30*(1), 40–49. https://doi.org/10.1177/1049909112444301.

Chapple, A., Evans, J., McPherson, A., & Payne, S. (2011). Patients with pancreatic cancer and relatives talk about preferred place of death and what influenced their preferences: A qualitative study. *BMJ Supportive & Palliative Care*, *1*(3), 291–295. https://doi.org/10.1136/bmjspcare-2011-000091.

Cipolletta, S., & Oprandi, N. (2014). What is a good death? Health care professionals' narrations on end-of-life care. *Death Studies*, *38*(1–5), 20–27. https://doi.org/10.1080/07481187.2012.707166.

Davies, B., Clarke, D., Connaughty, S., Cook, K., MacKenzie, B., McCormick, J., ... Stutzer, C. (1996). Caring for dying children: nurses' experiences. *Pediatric Nursing*, *22*(6), 500–507.

Dedoose (2016). *Web application for managing, analyzing, and presenting qualitative and mixed method research data. Vol 7.0.23.*Los Angeles, CAL: SocioCultural Research Consultants, LLC.

Del Greco, L., Walop, W., & McCarthy, R. H. (1987). Questionnaire development: 2. Validity and reliability. *CMAJ: Canadian Medical Association Journal = Journal de l'Association Medicale Canadienne*, *136*(7), 699–700.

DelVecchio Good, M. J., Gadmer, N. M., Ruopp, P., Lakoma, M., Sullivan, A. M., Redinbaugh, E., ... Block, S. D. (2004). Narrative nuances on good and bad deaths: internists' tales from high-technology work places. *Social Science & Medicine (1982)*, *58*(5), 939–953.

Eden, L. M., & Callister, L. C. (2010). Parent involvement in end-of-life care and decision making in the newborn intensive care unit: An integrative review. *The Journal of Perinatal Education*, *19*(1), 29–39. https://doi.org/10.1624/105812410X481546.

Epstein, E. G. (2008). End-of-life experiences of nurses and physicians in the newborn intensive care unit. *Journal of Perinatology: Official Journal of the California Perinatal Association*, *28*(11), 771–778. https://doi.org/10.1038/jp.2008.96.

Fang, M. L., Sixsmith, J., Sinclair, S., & Horst, G. (2016). A knowledge synthesis of culturally- and spiritually-sensitive end-of-life care: Findings from a scoping review. *BMC Geriatrics*, *16*, 107. https://doi.org/10.1186/s12877-016-0282-6.

Feudtner, C., Kang, T. I., Hexem, K. R., Friedrichsdorf, S. J., Osenga, K., Siden, H., & Wolfe, J. (2011). Pediatric palliative care patients: A prospective multicenter cohort study. *Pediatrics*, *127*(6), 1094–1101. https://doi.org/10.1542/peds.2010-3225.

Fielding, N. G., & Lee, R. M. (1998). *Computer analysis and qualitative research.* London: SAGE.

Fins, J. J., & Solomon, M. Z. (2001). Communication in intensive care settings: The challenge of futility disputes. *Critical Care Medicine*, *29*(2 Suppl), N10–N15.

Garcia, J., Evans, J., & Reshaw, M. (2004). "Is there anything Else you would like to tell us" – Methodological issues in the use of free-text comments from postal surveys. *Quality & Quantity*, *38*(2), 113–125. https://doi.org/10.1023/B:QUQU.0000019394.78970.df.

Garros, D. (2003). A "good" death in pediatric ICU: Is it possible? *Jornal de Pediatria*, *79* (Suppl. 2), S243–S254.

Gott, M., Small, N., Barnes, S., Payne, S., & Seamark, D. (2008). Older people's views of a good death in heart failure: Implications for palliative care provision. *Social Science & Medicine (1982)*, *67*(7), 1113–1121. https://doi.org/10.1016/j.socscimed.2008.05.024.

Govindan, M., Keefer, P., Sturza, J., & Malas, N. (2018). Effective debriefing: Empowering trainees to process distressing events. *Academic Pediatrics*, *18*(5), e36–e37. https://doi.org/10.1016/j.acap.2018.04.100.

Granda-Cameron, C., & Houldin, A. (2012). Concept analysis of good death in terminally ill patients. *The American Journal of Hospice & Palliative Care*, *29*(8), 632–639. https://doi.org/10.1177/1049909111434976.

Hechler, T., Blankenburg, M., Friedrichsdorf, S., Garske, D., Hübner, B., Menke, A., ... Zernikow, B. (2008). Parents' perspective on symptoms, quality of life, characteristics of death and end-of-life decisions for children dying from cancer. *Klinische Pädiatrie*, *220*(3), 166–174. https://doi.org/10.1055/s-2008-1065347.

Hemati, Z., Ashouri, E., AllahBakhshian, M., Pourfarzad, Z., Shirani, F., Safazadeh, S., ... Taleghani, F. (2016). Dying with dignity: A concept analysis. *Journal of Clinical Nursing*, *25*(9–10), 1218–1228. https://doi.org/10.1111/jocn.13143.

Horne, G., Seymour, J., & Payne, S. (2012). Maintaining integrity in the face of death: A grounded theory to explain the perspectives of people affected by lung cancer about the expression of wishes for end of life care. *International Journal of Nursing Studies*, *49*(6), 718–726. https://doi.org/10.1016/j.ijnurstu.2011.12.003.

Ito, Y., Okuyama, T., Ito, Y., Kamei, M., Nakaguchi, T., Sugano, K., & Akechi, T. (2015). Good death for children with cancer: A qualitative study. *Japanese Journal of Clinical Oncology*, *45*(4), 349–355. https://doi.org/10.1093/jjco/hyu223.

Jackson, V. A., Sullivan, A. M., Gadmer, N. M., Seltzer, D., Mitchell, A. M., Lakoma, M. D., ... Block, S. D. (2005). "It was haunting…": physicians' descriptions of emotionally powerful patient deaths. *Academic Medicine: Journal of the Association of American Medical Colleges*, *80*(7), 648–656.

Koesel, N., & Link, M. (2014). Conflicts in goals of Care at the end of life: Are aggressive life-prolonging interventions and a "Good death" compatible? *Journal of Hospice & Palliative Nursing*, *16*(6), 330–335. https://doi.org/10.1097/NJH.0000000000000068.

Kornfeld, D. S. (1977). The hospital environment: Its impact on the patient. In R. H. Moos (Ed.), *Coping with physical illness* (pp. 237–249). Boston, MA: Springer US. https://doi.org/10.1007/978-1-4684-2256-6_16.

Kreicbergs, U., Valdimarsdóttir, U., Onelöv, E., Henter, J. -I., & Steineck, G. (2004). Talking about death with children who have severe malignant disease. *The New England Journal of Medicine*, *351*(12), 1175–1186. https://doi.org/10.1056/NEJMoa040366.

Kukora, S. K., Laventhal, N., Keefer, P. M., & Firn, J. I. (2018). Transgressing moral imperatives: Ethical stress, virtues and values conflict in pediatric death. *Pediatric Ethicscope*, *31*(1), 38–50.

Langley-Evans, A., & Payne, S. (1997). Light-hearted death talk in a palliative day care context. *Journal of Advanced Nursing*, *26*(6), 1091–1097.

Lee, K. J., & Dupree, C. Y. (2008). Staff experiences with end-of-life care in the pediatric intensive care unit. *Journal of Palliative Medicine*, *11*(7), 986–990. https://doi.org/10.1089/jpm.2007.0283.

Low, J. T., & Payne, S. (1996). The good and bad death perceptions of health professionals working in palliative care. *European Journal of Cancer Care*, *5*(4), 237–241.

Meadors, P., & Lamson, A. (2008). Compassion fatigue and secondary traumatization: Provider self-care on intensive care units for children. *Journal of Pediatric Health Care: Official Publication of National Association of Pediatric Nurse Associates & Practitioners*, *22*(1), 24–34. https://doi.org/10.1016/j.pedhc.2007.01.006.

Meier, E. A., Gallegos, J. V., Thomas, L. P. M., Depp, C. A., Irwin, S. A., & Jeste, D. V. (2016). Defining a good death (successful dying): Literature review and a call for research and public dialogue. *The American Journal of Geriatric Psychiatry: Official Journal of the American Association for Geriatric Psychiatry*, *24*(4), 261–271. https://doi.org/10.1016/j.jagp.2016.01.135.

Munn, J. C., Dobbs, D., Meier, A., Williams, C. S., Biola, H., & Zimmerman, S. (2008). The end-of-life experience in long-term care: Five themes identified from focus groups with residents, family members, and staff. *The Gerontologist*, *48*(4), 485–494.

Murphy, S., Xu, J., Kochanek, K., Curtin, S., & Arias, E. (2017). Deaths: Final data for 2015. *National Vital Statistics Reports. Vol. 66.*. Hyattsville, MD: National Center for Health Statistics no 6.

O'Cathain, A., & Thomas, K. J. (2004). "Any other comments?" open questions on questionnaires – A bane or a bonus to research? *BMC Medical Research Methodology*, *4*(1). https://doi.org/10.1186/1471-2288-4-25.

O'Reilly, M., & Parker, N. (2013). 'Unsatisfactory saturation': A critical exploration of the notion of saturated sample sizes in qualitative research. *Qualitative Research*, *13*(2), 190–197. https://doi.org/10.1177/1468794112446106.

Payne, S. A., Dean, S. J., & Kalus, C. (1998). A comparative study of death anxiety in hospice and emergency nurses. *Journal of Advanced Nursing*, *28*(4), 700–706.

Payne, S. A., Langley-Evans, A., & Hillier, R. (1996). Perceptions of a "good" death: A comparative study of the views of hospice staff and patients. *Palliative Medicine*, *10*(4), 307–312.

Peters, L., Cant, R., Payne, S., O'Connor, M., McDermott, F., Hood, K., & Shimoinaba, K. (2013a). How death anxiety impacts nurses' caring for patients at the end of life: A review of literature. *The Open Nursing Journal*, *7*, 14–21. https://doi.org/10.2174/1874434601307010014.

Peters, L., Cant, R., Payne, S., O'Connor, M., McDermott, F., Hood, K., & Shimoinaba, K. (2013b). Emergency and palliative care nurses' levels of anxiety about death and coping with death: A questionnaire survey. *Australasian Emergency Nursing Journal: AENJ*, *16*(4), 152–159. https://doi.org/10.1016/j.aenj.2013.08.001.

Pituch, K., Halsey, M., Keefer, P., & Azim, J. (2016). E03-D multi-disciplinary pediatric end-of-life training improves staff preparedness and lessens staff distress. *Journal of Pain and Symptom Management*, *52*(6), e40–e41. https://doi.org/10.1016/j.jpainsymman.2016.10.111.

Qualtrics, Provo, Utah, USA (2016). Available from http://www.qualtrics.com.

Reinke, L. F., Uman, J., Udris, E. M., Moss, B. R., & Au, D. H. (2013). Preferences for death and dying among veterans with chronic obstructive pulmonary disease. *The American Journal of Hospice & Palliative Care*, *30*(8), 768–772. https://doi.org/10.1177/1049909112471579.

Robins, P. M., Meltzer, L., & Zelikovsky, N. (2009). The experience of secondary traumatic stress upon care providers working within a children's hospital. *Journal of Pediatric Nursing*, *24*(4), 270–279. https://doi.org/10.1016/j.pedn.2008.03.007.

Rosenthal, S. A., & Nolan, M. T. (2013). A meta-ethnography and theory of parental ethical decision making in the neonatal intensive care unit. *Journal of Obstetric, Gynecologic, and Neonatal Nursing: JOGNN*, *42*(4), 492–502. https://doi.org/10.1111/1552-6909.12222.

Shaw, K., Ritchie, D., & Adams, G. (2011). Does witnessing resuscitation help parents come to terms with the death of their child? A review of the literature. *Intensive & Critical Care Nursing*, *27*(5), 253–262. https://doi.org/10.1016/j.iccn.2011.05.001.

Sinkovics, R. R., & Alfoldi, E. A. (2012). Progressive focusing and trustworthiness in qualitative research: The enabling role of computer-assisted qualitative data analysis software (CAQDAS). *Management International Review*, *52*(6), 817–845. https://doi.org/10.1007/s11575-012-0140-5.

Small, N., Barnes, S., Gott, M., Payne, S., Parker, C., Seamark, D., & Gariballa, S. (2009). Dying, death and bereavement: A qualitative study of the views of carers of people with heart failure in the UK. *BMC Palliative Care*, *8*, 6. https://doi.org/10.1186/1472-684X-8-6.

Sundin-Huard, D., & Fahy, K. (1999). Moral distress, advocacy and burnout: Theorizing the relationships. *International Journal of Nursing Practice*, *5*(1), 8–13.

Tenzek, K. E., & Depner, R. (2017). Still searching: A meta-synthesis of a good death from the bereaved family member perspective. *Behavioral Sciences (Basel, Switzerland)*, *7*(2). https://doi.org/10.3390/bs7020025.

Valdez-Martinez, E., Noyes, J., & Bedolla, M. (2014). When to stop? Decision-making when children's cancer treatment is no longer curative: A mixed-method systematic review. *BMC Pediatrics*, *14*, 124. https://doi.org/10.1186/1471-2431-14-124.

Wallace, J. E., Lemaire, J. B., & Ghali, W. A. (2009). Physician wellness: A missing quality indicator. *Lancet (London, England)*, *374*(9702), 1714–1721. https://doi.org/10.1016/S0140-6736(09)61424-0.

Weintraub, A. S., Geithner, E. M., Stroustrup, A., & Waldman, E. D. (2016). Compassion fatigue, burnout and compassion satisfaction in neonatologists in the US. *Journal of Perinatology*. https://doi.org/10.1038/jp.2016.121.

Welch, S. B. (2008). Can the death of a child be good? *Journal of Pediatric Nursing*, *23*(2), 120–125. https://doi.org/10.1016/j.pedn.2007.08.015.

Yam, B. M., Rossiter, J. C., & Cheung, K. Y. (2001). Caring for dying infants: Experiences of neonatal intensive care nurses in Hong Kong. *Journal of Clinical Nursing*, *10*(5), 651–659.