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Safety in Pediatric Hospice and Palliative Care: A Qualitative Study

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Introduction: Patient safety is extensively studied in both adults and pediatric medicine; however, knowledge is limited regarding particular safety events in pediatric hospice and palliative care (HPC). Additionally, pediatric HPC lacks a unified definition of safe care. This qualitative study sought to explore caregiver views regarding safe care in pediatric HPC. **Methods:** This is a secondary analysis of qualitative data from a multisite study utilizing semistructured interview data to evaluate parental perspectives of quality in pediatric home-based HPC programs across 3 different pediatric tertiary care hospitals. Eligible participants included parents and caregivers of children who were enrolled in a pediatric home-based hospice and palliative care program (HBHPC) from 2012 to 2016. The analysis was done using grounded theory methodology. **Results:** Forty-three parents participated in 39 interviews across all 3 sites; 19 families were bereaved. Responses to the prompt regarding safe care produced 8 unique domains encompassing parental definitions of safe care in pediatric HPC. **Discussion:** Parents of children in HPC programs describe "safe care" in novel ways, some of which echo Maslow's hierarchy of needs. The use of traditional hospital safety measures for patients receiving HPC could undermine the patient's goals or dignity, ultimately leading to harm to the patient. **Concluding summary:** Patients' and families' unique goals and values must be considered when defining safety for children in this population. Future studies should continue to explore family perspectives of safety in the hospital and ambulatory settings and seek to identify measurable indicators in safety which are truly patient- and family-centered. *(Pediatr Qual Saf 2020;4:e328; doi: 10.1097/pq9.0000000000000328; Published online 10 July, 2020.)*

INTRODUCTION

The World Health Organization defines patient safety as "the absence of preventable harm to a patient during the process of healthcare, and the reduction of risk of unnecessary harm associated with healthcare to an acceptable minimum."[1] Safety

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in healthcare is typically measured or described in terms of rates of morbidity and mortality. However, since hospice and palliative care (HPC) patients are, by definition, at high risk for morbidity and mortality, these measures fall short. This population arguably deserves at least as much attention to safety, given their vulnerability and the levels of stress inherent in their care. A clear, relevant definition of safety, based on both provider and patient/caregiver perspectives, is required to identify measures of safe care and harm for patients receiving HPC.

Safety issues have been described in adults receiving HPC. A review of 1,072 safety incident reports for patients receiving after-hours palliative care (PC) from the National Reporting and Learning System (NRLS) in the UK indicated that failure to follow protocols and lack of skills/confidence in staff were common drivers of medication issues, delay in cares, and problems with information transfer.[2] These incidents incurred harm, with increased pain and emotional or psychological distress featured prominently.[2] Additionally, a retrospective study of notes from PC inpatient services found that 62% of adult patients receiving care suffered from adverse events such as falls, urinary retention, hypotension, and decreased consciousness.[3] The stress induced by medical errors may be more consequential for patients receiving HPC because it can add to the distress of parents and caregivers, increase the suffering of the patient, and impede the delivery of high-quality end-of-life care.[4]

Goal-concordant care is an essential part of a high-quality healthcare system; failure to align care with family goals is an urgent medical error.[5] Another retrospective study of the NRLS specifically evaluated safety incidents regarding advanced care plans and found that lack of staff knowledge, confidence, and competence were contributing factors. Harmful outcomes identified in this review involved goal-discordant care, especially inappropriate receipt of cardiopulmonary resuscitation.[6] In pediatrics, the safest hospitals appropriately focus on widespread training and implementation of early warning systems (eg, Pediatric Early Warning System scores) to predict with high reliability which patients may decompensate, require transfer to a critical care unit and/or experience cardiac arrest.[7–9] These systems have undoubtedly saved countless lives. However, for children with goals and orders to limit life-sustaining medical interventions, an assumption of a "one-size-fits-all" approach to safety is inappropriate. "Safety culture" in these institutions must also include a definition and understanding of how to approach the care of these children, with the same concern and attention that is applied to typical children. Such definitions may be more accepting of a more traditional type of risk (eg, aspiration) to assure acquisition of another goal (eg, pleasure of eating), and hospital systems need malleability to explore this benefit/burden calculus with families.

Recommendations regarding the delivery of high-quality pediatric HPC state that patient safety and quality be a cornerstone of a family- and patient-centered programs serving children with life-threatening illnesses.[10] Although researchers have extensively studied patient safety in adult and pediatric care, little is known about particular safety events in pediatric HPC. Additionally, pediatric HPC lacks a unified definition of safe care. This qualitative study sought to explore caregiver views regarding safe care in pediatric HPC. As we designed our methods to be hypothesis-generating, rather than hypothesis-driven, there were no a priori hypotheses stated.

METHODS

The authors have previously published and described study procedures in detail.[11] Briefly, this is a subanalysis of a more extensive qualitative study evaluating parental perspectives of quality in pediatric home-based HPC programs. Three different pediatric tertiary care hospitals in Ohio served as study sites, and each institution's institutional review board (IRB) approved the study. Eligible participants included parents and caregivers of children who were enrolled in a pediatric home-based hospice and PC program (HBHPC) from 2012 to 2016. The study staff conducted semistructured interviews at a time and location convenient to the participant. Participants provided informed consent before the start of the interview. Two members of the study staff conducted and digitally recorded all interviews. The authors developed a semi-structured interview guide using known literature, clinical

experiences, and study aims, including the prompt, "When you think about home-based hospice and palliative care, what does the term 'safe care' mean to you?" A HIPAA-compliant vendor transcribed the digitally-recorded interviews. Study staff verified and de-identified the interviews.

ANALYSIS

This qualitative study used grounded theory methodology for analysis.[12–14] Transcripts were analyzed and coded by at least 3 trained study staff members with conflicting views resolved by consensus. The authors completed data collection and analysis simultaneously to allow for the iterative development of the interview guide based on emergent themes. Data were evaluated by sorting codes (verbatim utterances) into common themes. For this secondary analysis, codes related to safety measures were analyzed. All analysis was done using NVivo 12 software.

RESULTS

Forty-three parents participated in 39 interviews across all 3 sites; 19 (49%) families were bereaved. Two (5%) participants were male and 32 (82%) female. Additionally, five interviews were completed as caregiver dyads. Specific data regarding the participant demographics can be found in Table 1. Responses to the prompt regarding safe care produced 8 unique domains encompassing parental definitions of safe care in pediatric HPC. Exemplar quotes further characterize domains.

SAFETY OF PHYSICAL ENVIRONMENT

Some parents described aspects of the physical environment and the importance of home precautions as contributing to safe care.

Doing what's best for the child, doing no harm, doing it in a manner that does not hurt him.

Keeping [N.] safe, making us aware of things that maybe we wouldn't think about…like batteries in the fire alarm.

One time, they told us we couldn't keep our oxygen tanks upright. So…they recognized maybe something wasn't safe…They tried to make sure we were maybe safer than we would've been otherwise.

Table 1. Number of Interviews and Interviewee Identity

Characteristic	N (%)
Gender	
Male	2 (5)
Female	32 (82)
Dyad	5 (13)
Race/ethnicity	
Caucasian	40 (91)
Black	3 (7)
Other	1 (2)
Status	
Active	20 (51)
Bereaved	19 (49)

HOMECARE PREVENTS EXPOSURE TO ILLNESS

Many parents emphasized the importance of limiting infectious exposure to their children; having home-based care kept their child safer because children are exposed to fewer pathogens.

If I have to drag him down to the hospital…, it increases his risk for infection, especially in the middle of winter. We don't like to take him to the hospital. It improves overall infection potential if you keep them away from the hospital.

Just protecting her against things…like washing or sanitizing hands when they come in, or they're ready to leave, if they're sick they don't come, they'll send somebody else. That's what safe care means to me.

I always felt safe with them, and [N.] has as well… They sterilize everything that they're going to use like the stethoscope and the temperature things, and they're logging things.

COMPETENT CARE

Parents felt safe when they believed that the team was competent and confident in caring for a child with a unique illness. Some stated they felt at ease when nurses would finish all tasks before leaving. Parent/caregivers reported that it gave them confidence in the team when the team spotted things that the parent may not have noticed. Others described feeling safe when the team would try to understand their child's particular condition and voiced trust that the team members would do the proper research before implementing treatments.

Safe care means knowing my child, knowing what his condition is, understanding his condition, and not taking any action that's going to aggravate his condition.

We have to worry about her anxieties and all that type of stuff. The nurses that come, they are aware and try to accommodate…sometimes they will say 'Look, I'm not leaving the house until this is done.'

[Palliative team] perceives caution before they suggest something like 'we're not going to conclusively say yes or no until we go do some extra research.' So, to come up with ideas [before implementing them], they do the work first.

MEDICATION SAFETY

Several parents recounted the importance of safety regarding the child's medications. They wanted to ensure that their child was receiving proper medications and that the child was not at risk for drug interactions. Some parents verbalized that they wanted medications to maintain comfort, but not hasten the child's death.

I would say first and foremost, it's making sure all the medicines interact with each other ok…I always felt like safe care was the management of her medicines in a conscientious manner.

Just being there to make sure we're not giving too much medication or too little medication. That we have the equipment that we need to provide medication or medically required…I would say those are the probably biggest things as far as making sure we are safe.

We're not going to dose a triple what we should dose them to basically progress her death.

MAINTAINING COMFORT AND PREVENTING HARM

Parents described that their idea of safe care meant that their children were comfortable, with their dignity maintained. Others felt it was important for the HPC team not to harm their child. They discussed the importance of the team being careful in treating a medically fragile child to avoid incurring any physical harm.

I would say [safe care] is an extension of comfort care.

I think it means that the person is allow to transition with dignity and safely. There's somebody kind of helping you and kind of watching you, in a good way.

It would be doing what was best to keep the child safe…care that keeps the child both safe and protected and in a good place.

TRUST OF PEOPLE IN THE HOME

Multiple parents discussed the importance of being able to trust the HBHPC caregiver in their home. Parents felt the need to feel safe when inviting people into their homes. They identified character as an essential way to distinguish who was trustworthy and who was not. Others felt the need for increased security in the home while the staff was present to ensure their child was safe.

I kind of think about the character of people that are coming into my home or the roles as far as why they're here and do they actually care about us and also are they competent.

I've always had cameras because she can't talk, she can't do anything to defend herself. She's at your total mercy.

With [the program] coming to our home all the time, it was important to me to feel safe inviting people into my home…that gut feeling…you know, they're not hurting or doing anything detrimental to anyone.

GOAL-CONCORDANT CARE

Some parents emphasized the importance of the care team keeping their child's and family's goals in mind throughout their time in a hospice and/or palliative care program. They delineated the team's importance, not only understanding their goals but also feeling supported by the team in the goals they had made.

That whatever decision we make, it's OK, and they're there to support us.

The pharmacy at [hospital] was like, so you do realize this is a really high dose of phenobarbital and could compromise respiration. I'm sure it's because…we're kind of different…but it's like, I'm fine. Right. I get it.

EMOTIONAL SAFETY

Feelings of emotional safety were also crucial to several participants. Caregivers described feeling safe when they thought they could trust the providers and the team. Similarly, participants felt that safe care meant they could confide in the team and talk to them about their struggles.

Safe as in trusting, like you can share something with them and trusting that they're not going to take that information and manipulate it. Honorable, truthful.

When I think of safe care, it's care that you are receiving is helpful, but you don't really have to worry. Like it's a safe place, it's safe people to talk to, and pretty much they'll help you in all of your aspects of care.

DISCUSSION

This study was a subanalysis of a more extensive study that explored how parents describe and define high-quality pediatric HBHPC, focusing specifically on how parents define "safe care" in the home. We found that parents of children in HPC programs describe "safe care" in novel ways. To our knowledge, this is the first paper describing parental perspectives of safety in pediatrics.

Integrating patient- and parent-prioritized domains of safety into routine HPC would likely require a reimagining of our current safety measures and how we define patient harm. Importantly, the emergent 8 domains of safe care may be relevant in providing patient- and family-centered care to all children, not just those receiving HPC. For example, parents prioritized the safety of the physical environment—in this case, their home—in describing safe care. For a hospital system, one traditional measure of harm in the domain of "Safety of the Physical Environment" is the rate of patient falls. If someone is dying, though, that patient may prioritize the dignity conferred by walking to a bedside commode over the risk of a fall. Thus, the use of traditional hospital safety measures for patients receiving HPC could undermine patient goals. Put another way, a fall with this patient should not be considered an error or harm in the same way that a typical fall might be, depending on the patient's goals. Table 2 provides other examples of traditional hospital-centered measures or considerations, alongside reimagined parent and patient-centered examples for each of the eight domains of safety in pediatric HPC.

The authors noted a resemblance in the way parents described safety to Maslow's hierarchy of needs (Fig. 1). Maslow's hierarchy of needs is a 5-tiered pyramid model used to explain how humans intrinsically partake in behaviors to fulfill different motivations. For humans to actualize in a particular level, each previous level must be satisfied.[15] The domains of safety parents described map similarly to these concepts. When asked about safety, parents expressed the importance of the physical environment, avoiding illness, and trusting people in the home (similar to physiologic needs), the importance of staff competence, medication safety and avoiding harm (similar to safety needs), and emotional safety and the provision of goal-concordant care (similar to belongingness, esteem, and self-actualization). Perhaps, it should not be surprising that laypersons conceptualize safety in these ways. It does, however, offer a new paradigm when considering what patients and their families need from the healthcare system to feel safe, particularly in HPC and end-of-life care when parents are particularly vulnerable. Previous studies have discussed this connection between HPC and Maslow's hierarchy of needs. Zalenski and Raspa[16] suggest there are 5 levels of palliative care needs: (1) relief from physical pain; (2) safety in a personal and social sense; (3) giving and receiving love and affection; (4) self-esteem and respect; and (5) self-actualization and transcendence. Establishing this hierarchy with each person can allow them to achieve their personal goals before the end of life. Poor quality of life, especially in HPC programs, hinders a patient from achieving a "good death," or a death concordant with one's goals.[17]

Our findings that parents name the provision of care by providers competent in caring for children with rare diseases, goal-concordant care, and trust of people in the home as safety priorities echo findings from the literature in adult HPC. The reports from the NRLS and Sweden highlight the importance of skilled, competent staff in providing care that is goal-concordant, medically appropriate, and engenders emotional trust by the patient.[2,3,6,18] Specifically, an evaluation of the use of the Integrated Palliative Outcome Scale (IPOS) in patients receiving PC in Sweden found that the repeated use of this communication tool-promoted safe care. Use of the communication tool tailored care provided to individual needs, thus making patients feel more confident.[19] Clear, ongoing communication with families is paramount in determining what goals should guide a treatment plan and in providing goal-concordant care. In pediatrics, the additional step of ensuring that these goals are communicated clearly to all providers caring for the child is also critical. The parents included in this study remind us that assumed or poorly communicated goals of care can indeed lead to harm to their child, and that the provision of goal-concordant care should be prioritized at least alongside, if not above, other metrics for care in the home, clinic, and hospital.

This study has several limitations. As previously described, participants identified primarily as female, mothers, Caucasian, and living in Ohio.[11] Study staff queried parents specifically about HPC that occurred in the home, not in other settings. Importantly, we appreciate that many parents, who are primarily lay people, do not wield a specific language to describe safety in healthcare;

Table 2. Domains of Safety as Prioritized by Parents with Traditional Examples from the Inpatient Setting and Novel Examples that Are Patient- and Family-centered

Parent-prioritized Safety Domain	Traditional Hospital-centered Example	Parent- and Patient-centered HPC Example that Conflicts with Traditional Concept
Safety of physical environment	Fall rate	Patient refuses to use bedside commode due to definition of dignity and risks falling to walk to bathroom
Homecare prevents illness	Central-line associated blood stream infection rate	Parents accept risk of staying home with fever for benefit of avoiding flu season in clinic or exposure in the Emergency Department
Medication safety	Polypharmacy	Parents accept of risk of respiratory sedation with antiepileptics for benefit of seizure prevention at end of life
Competent care	Team members trained in chemotherapy administration	Team members comfortable caring for child with rare disease
Maintaining comfort and preventing harm	Spinal fusion encouraged in patient with muscular dystrophy	Parent opts for pharmacologic versus surgical management of scoliosis
	G-tube encouraged in infant with poor oral intake	Families prefer nasogastric tube to avoid risks of surgery or accept risk of aspiration to maintain enjoyment from eating
	Tracheostomy encouraged for patient with laryngomalacia in setting of underlying Batten Disease	Parent chooses noninvasive ventilatory support to maintain ability to vocalize and eat by mouth
Trust of people in the home	Direct and indirect supervision of employee interactions and interventions	Families feel physically and emotionally safe inviting team members into their homes 24/7
Goal concordant care	Gastroenterology encourages increasing feeds to improve weight gain/reverse failure to thrive	Family accepts cachexia and prioritizes feeding for comfort
Emotional safety	Consult on chart for behavioral medicine	Family has trust in the medical team to share vulnerably without judgment
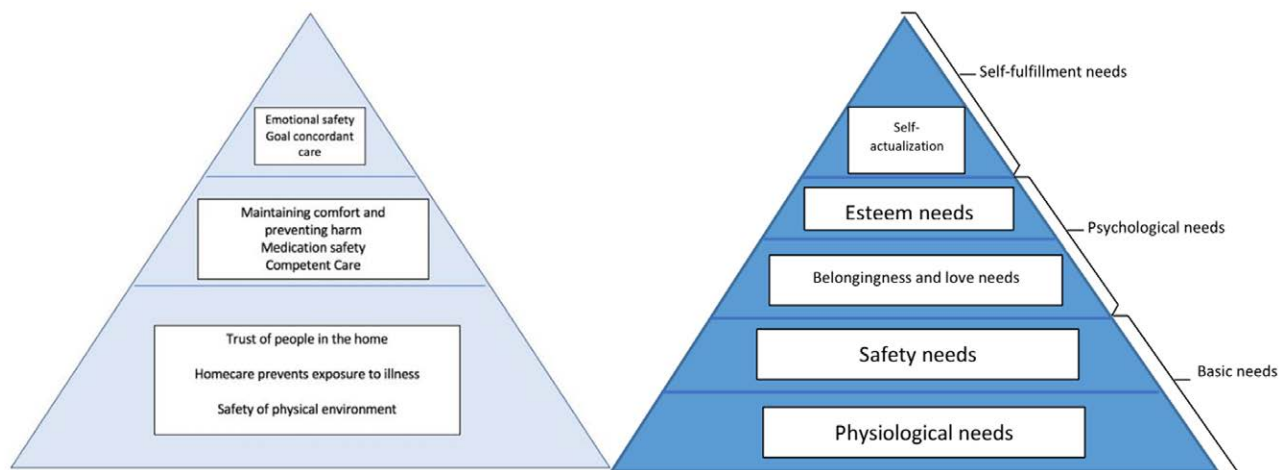
Fig. 1. Comparison of Maslow's hierarchy of needs and parent-prioritized domains of safety.

we extrapolated our findings from our understanding of their responses. Future studies should continue to explore parental perspectives of safety in the hospital and ambulatory settings and seek to identify measurable indicators of safety that are truly patient- and family-centered.

Providers in both pediatric HPC and referring specialties must understand the concept of safety in regards to pediatric HPC. Although traditional safety definitions may be applicable, providers should be aware of the potential differences in safety concerns for HPC patients. There should be transparency in how pediatric HPC providers define, measure, and address safety in all settings for HPC patients. Finally, defining safe care according to the patient or caregiver goals is a novel approach to safety culture. The implementation of these findings requires acceptance and adoption by stakeholders across healthcare and augmentation of current systems. Protecting patients from harm is equivalent to providing high-quality care; only when we understand nuanced aspects of

safety, tailored to each family's values, will our most vulnerable patients truly be protected from harm.

DISCLOSURE

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