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Compassionate Design: Utilizing Design Thinking to Preserve Sanctity, Dignity, and Personhood When Children Die

Daniel H. Grossoehme, DMin*†; Melissa S. Mark, MD‡§; Blake Lane, PhD¶;
Allison Rednour, MDes¶; Rachel Thienprayoon, MD*‖*

Abstract

Introduction: Greater than 70% of children who die in our institution annually die in an intensive care unit (ICU) setting. Family privacy, visitation policies, and an inability to perform religious rituals in the ICU are barriers to provide children with culturally competent, family-centered care when a child dies. The goal of this project was to profoundly understand family and staff experiences surrounding pediatric death in our institution to identify unique opportunities to design improved, novel delivery models of pediatric end of life (EOL) care. **Methods:** This project utilized a structured process model based on the Vogel and Cagan's 4-phase integrated new product development process model. The 4 phases are identifying, understanding, conceptualizing, and realizing. We utilized an adaptation of this process model that relies on human-centered and design thinking methodologies in 3 phases: research, ideation, and refinement of a process or product opportunity. **Results:** There were 2 primary results of this project: 5 process and opportunity areas to improve the EOL experience across the hospital, and a set of criteria and considerations for a dedicated EOL space. **Discussion:** Sometimes, the best outcome we can provide for a child and their family is a peaceful, dignified death. This project utilized human-centered design to create improved process outcomes and to design a dedicated EOL space for children who die in the hospital. Offering grieving families quiet, private time with their child in a beautiful, dignified, peaceful location enables the beginning of improved bereavement outcomes for the family and staff. *(Pediatr Qual Saf 2020;4:e317; doi: 10.1097/pq9.0000000000000317; Published online 8 July, 2020.)*

From the *Haslinger Family Pediatric Palliative Care Center, Akron Children's Hospital, Akron, Ohio; †Rebecca D. Considine Research Institute, Akron Children's Hospital, Akron, Ohio; ‡Eastern Virginia Medical School, Norfolk, Va.; §Children's Hospital of The King's Daughters, Norfolk, Va.; ¶Livewell Collaborative, Cincinnati, Ohio; ‖Department of Anesthesia, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio; and *University of Cincinnati College of Medicine, Cincinnati, Ohio

*Corresponding author. Address: Daniel H. Grossoehme, DMin, Haslinger Family Pediatric Palliative Care Center, Akron Children's Hospital, 1 Perkins Square, Akron, OH 44308
PH: 1-330-543-0356
Email: dgrossoehme@akronchildrens.org

INTRODUCTION

Pediatric hospitals' care for children and families usually equates "care" with "cure."[1] When a cure is not possible, care means focusing on compassion and comfort. Children deserve a beautiful, dignified place to die; their families deserve a quiet, peaceful place to say goodbye. However, the majority of children who die in children's hospitals do so in an intensive care unit (ICU) setting.[2] A total of 445 patients affiliated with this institution died in 2016; 169 died on inpatient units within the hospital, of whom 73% died in an ICU. This fact presents clinicians from numerous disciplines with significant challenges.

Numerous factors influence parental experience and bereavement outcomes as a child approaches death and immediately afterward in this institution (Fig. 1). Memories of a child and the child's death critically impact the way a family grieves; positive experiences predict better bereavement outcomes.[3] Interviews with bereaved mothers identified four end of life (EOL) and postmortem care needs: (1) time with their dying child; (2) space and privacy with their dying child; (3) time with the child's body; and (4) space and privacy with their child's body.[3] Mothers reported "peace and serenity" following their child's death when their postmortem care needs were met.[4]
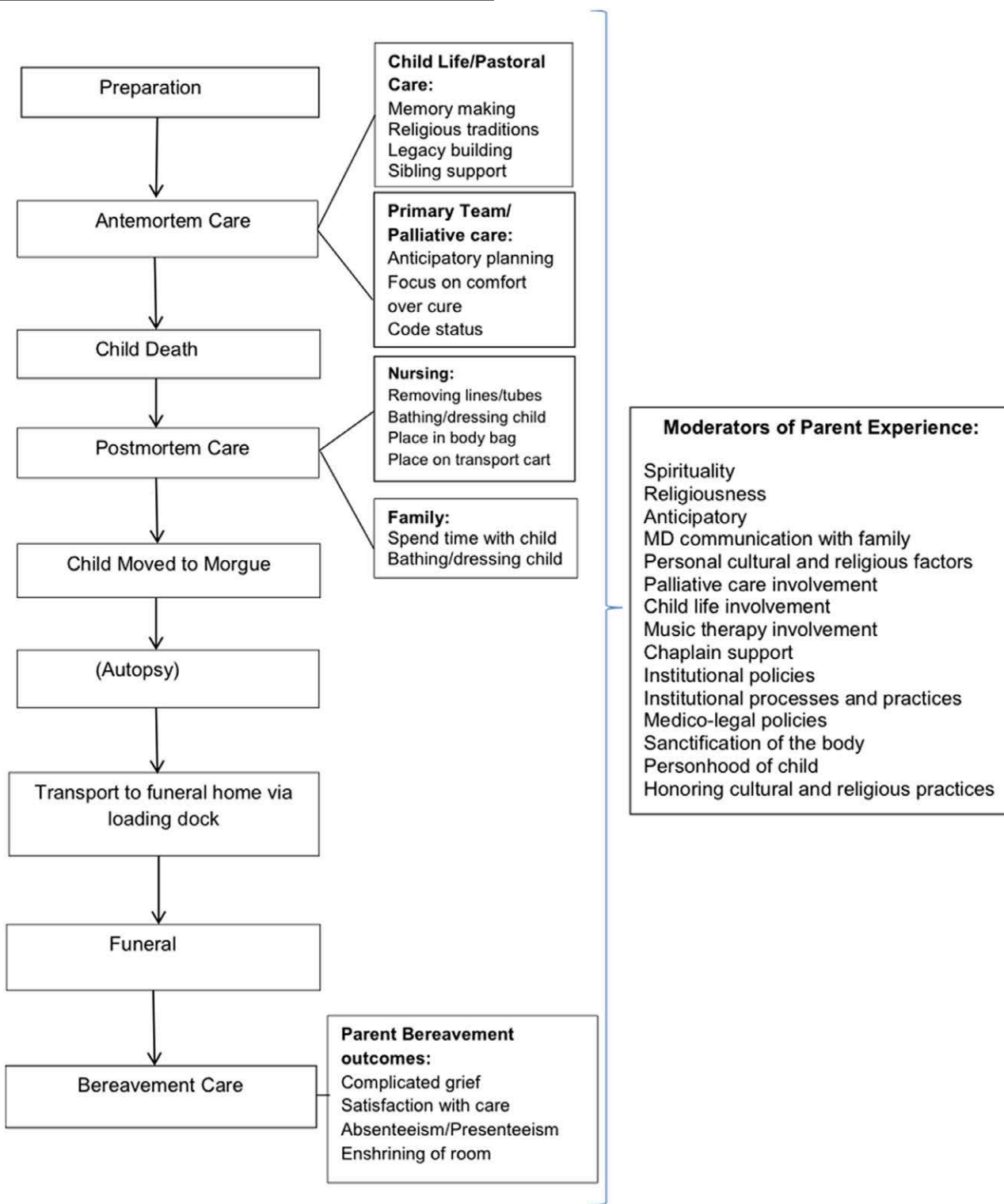
Fig. 1. Bereavement process and family experience.

The high percentage of children who died at this site's ICU reflects national pediatric death trends.[5] Contemporary approaches to pediatric EOL care are generally extrapolated from adult interventions and may not be appropriate for pediatric deaths.[6] This hospital lacks dedicated, quiet, private spaces for pediatric EOL, and spacious, separate areas for their family to gather. The inpatient visitation policy permits 24-hour access to only 4 primary support persons, and only 6 additional people may visit during visiting hours. When a child dies, these policies may be relaxed, but there are no standards for when to make exceptions. The influenza season presents

additional complexity. Nevertheless, for many families, "culturally competent" EOL care means allowing the dying child unlimited access to immediate and extended family, and friends.

After the child has died, removing intravenous and other lines and tubes, laying with and bathing the child, praying, and receiving family, all occur in the room where the child died. Ritual bathing of the body, required by some religions, is challenging to accommodate in a hospital bed, and there are no dedicated areas in the hospital for ritual bathing. Although staff (typically nursing or chaplaincy) tell families that they may remain in the room for "as long as they wish," the best practice is to transfer a child to a morgue or "cool room" within 4–6 hours.[7] During high census periods, staff may feel pressure to move a family from the room before the family may be ready. A mother of a child who died in an ICU at this site stated, "Their 'patient' had died…we weren't the patient. We felt that we had to go." The family must then leave the child in that room and return home without them. This transition is emotional for both parents and staff. One bereaved parent stated, "…the hardest thing I ever had to do is walk away from the hospital."[3]

Some religious/cultural practices dictate that the parents or faith leader accompany the body until burial, including accompanying the child's body to in the morgue. In this institution, the morgue is in the hospital basement, allowing funeral homes access to the loading dock. Depending on the child's location of death, the morgue may be in a separate patient care building. Chaplains described the route to this morgue as "unceremonious" and "stark, uninviting, and utilitarian." Some families have increasingly insisted on accompanying the child to the morgue, frequently related to religious/cultural reasons.

The goal of this project was to profoundly understand family and staff experiences surrounding pediatric death in our institution and to identify unique opportunities to design improved, novel delivery models of pediatric EOL care. This project was a collaboration with key stakeholders from this hospital and a nonprofit organization that utilizes a design-thinking process to co-create innovations aimed at improving health.[8]

METHODS

The hospital's institutional review board reviewed this study and determined it to be quality improvement work, not human subjects research. No institutional review board approval was required to proceed.

Participants

This project setting was a 675-bed academic pediatric medical center in the Midwest. Participants' recruitment proceeded by snowball sampling. Recruitment of bereaved parents proceeded with the recruitment of one bereaved parent well-known to the study team who had

previously expressed an interest. After that, other bereaved parents are known to that individual or to study staff members invited to participate. Study staff approached clinical managers to make them aware of the study and asked them for suggestions of clinical staff who might like to be involved. The roles of the clinical staff invited included an array of experiences across the institution's EOL journey. These staff were contacted individually and invited to participate. Knowledge of the project spread by word of mouth and other staff approached the team for participation.

The ratio of family to the staff participants was limited by our access to families open to participating in a study about what may have been a traumatic experience. The number of clinical staff participants was greater than family participants because the study intended to capture the diverse perspectives of staff experiencing the EOL journey from various lenses. The final ratio of fewer families to staff is not illustrative of the importance of one voice over another; the experiences and perspectives of the bereaved families were viewed with the utmost respect and concern throughout the study.

Procedures

We used Craig Vogel and John Cagan's structured 4-phase integrated new product development process model that begins with identifying an opportunity and ends with realizing that opportunity into a product.[9] The 4 phases are identifying, understanding, conceptualizing, and realizing. This project utilized an adaptation of this process model that relies on human-centered and design thinking methodologies. This process model is a multidisciplinary, 3-phase model focusing on research, ideation, and refinement of a process or product opportunity to develop technologically feasible and cost-effective solutions that address stakeholder needs.[10] Stakeholders include all users of a process or product. Design thinking methods include every stakeholder to ensure that solutions meet people's needs and are compatible with daily routines and workflow.

Phase 1: Research

Preparatory

The phase's goal was to understand the EOL process through primary and secondary research methods for design members of the study team from the nonprofit organizations to learn about EOL care issues in pediatrics. Two members of the study team (B.L. and A.R.) researched 24 examples of palliative care and EOL care from around the world. They conducted a literature search of 35 peer-reviewed articles about death and design, grieving, hospice care, and various cultural understandings of death and dying. The literature review intended to provide a deeper understanding of the current academic and professional discussion, and best practice recommendations or guidelines, occurring within the palliative care and EOL space. This review informed a more

empathic approach to interviewing staff and families and influenced later design considerations.

Study team clinical members provided photographs of EOL spaces at other institutions and solicited additional examples through pediatric chaplaincy and pediatric bereavement e-listserves with national and international membership. The literature review identified 3 key insights: support across the journey, understanding parent priorities, and bonding after death. Pediatric death is not an isolated event; it also includes the parents' entire journey from the emotional loss of their child to the physical separation from their child at the time of death. It consists of the social loss of their roles as parents and their cognitive loss of self-esteem.[11] Meyer et al[12] identified parent priorities for improving EOL care in the pediatric ICU. These priorities were honest and complete information, ready access to staff, communication/care coordination, staff emotional expression and support, preservation of the parent–child relationship's integrity, and spiritual faith.[12] Continued bonding with the child, especially with younger children and infants, is helpful to parents and may be facilitated by encouraging parents to speak to their child even after death.[13]

Qualitative Data Collection

Study team members interviewed both hospital staff and bereaved parents during the 16-week project. Hospital staff included hospitalists, nurses, geneticists, palliative care clinicians, intensivists, pathologist, chaplains, child life workers, social workers, bereavement coordinators, protective services (hospital security), and interpreters. A total of 22 hospital staff completed interviews; 5 bereaved parents completed interviews. Interviews were conducted with various critical informants at 3-time points throughout the project. Data were recorded by note-taking during interview sessions. Insights were translated on post-it notes and organized into themes and categories to identify patterns and overlap in the interviews.

During the interviews, stakeholders explained what they see, think, say, and do during each step of the end of life process. As the stakeholders reported their experiences, the team used a tool called an experience map[14] to organize insights with stakeholders during the interview. The participants drew from their own experiences to discuss problems that arose during their time with the hospital, identify areas of improvement, and conceptualize potential design interventions. The experience-mapping exercise targets interviewee's emotions by assessing how they felt, what they heard and saw, and what they did during the end of life process. It intends to "uncover, visualize, and better understand the target user's emotional experience."[15]

Data Analysis

Transcribed field notes were organized into themes. From the themes, the team used qualitative methods of coding to identify patterns, commonalities, and differences across the insights translated from the experience maps.[18] These translated insights were the key drivers for the results of the project. We identified 5 key areas of process improvements from the insights and suggestions collected from bereaved parents and clinical staff that the hospital could focus on to improve the EOL experience. Those focus areas were: establish an appropriate level of privacy and communication of privacy for families and patients; transition the mindset from caring for an ICU patient to creating a legacy for the child; provide adequate space and time for staff care; incorporate moments of parent control throughout the EOL process; and to standardize staff communication and care teams during the EOL process.

Phase 2: Ideation

During ideation, the team's goal was to profoundly understand the 5 key areas of process improvement identified for the hospital. The team interviewed 9 clinicians and 5 bereaved parents. The shift in clinical staff participation from 22 to 9 was based on the clinical staff's role and emphasized their direct engagement in the 5 key areas of process improvements. The 2 clinicians identified to participate in the ideation phase also participated during the research phase. The 5 bereaved parents were the same parents interviewed during the research phase of the study. The interview sessions consisted of interactive exercises, such as mood boards and theme development.

Mood boards are visual communications of the look and feel of final products or services. They trigger "analogical reconfigurations across the senses that support innovative solutions" during the product design process.[16] Mood boarding activity allowed participants to express what the ideal EOL process means to them through abstract images. The selection of images was chosen through an image search utilizing keywords extracted during the experience-mapping exercise (such as tranquility, peaceful, spiritual, intense, etc.) from the research phase. Participants selected images and curated their mood boards through creative expression. While selecting images, the interviewers prompted the participants with questions about what emotions, feelings, and experiences their selections evoked. Participant bias during this process was mitigated by recognizing that the narratives which emerged from the image selections were the most impactful outputs rather than the mood board themselves. The mood boards acted as a vessel to engage participants to create an open dialogue around potential subproducts and services for improving EOL processes.

After creating mood boards, interviewees and team members co-created potential subproducts and services by using the 5 opportunity areas identified during the research phase as a foundational platform. Participants were asked to describe narratives of difficulty related to the opportunity area, insight into what would improve their experience, and if they had a "magic wand," what

would be their ideal fix. The study team used the narratives from the mood board exercise and responses from the co-creation session to inform concepts for opportunity areas. The result of ideation was 12 conceptual ideas that address the 5 key opportunity areas identified in the research phase (see Table 1).

Phase 3: Refinement

During refinement, the team's goal was to create and test prototypes of the 12 concepts created during ideation. Low-resolution prototypes of potential lighting options, privacy indicators, and mental health reminders attached to everyday items were created and evaluated through feedback sessions. The 5 parents and 9 staff who participated in research and ideation also participated in this phase. Other hospital and resource planning departments were also included, to offer logistical perspectives for implementing the concepts. Creating and receiving feedback on prototypes of possible solutions promotes a shared vision of outcomes across stakeholder populations, helps test ideas quickly, and offers methods for iterative improvements.[17] Refinement sessions with clinical staff and families elicit ways to improve the prototypes and make the prototypes better fit the hospital workflow and family life. Barriers to consider for implementing the interventions from logistics within the hospital to habit adoption by staff and families were discussed. The final project results (prototype refinement) were driven by staff and family insight.

RESULTS

There were 2 primary results of this project: 5 process/opportunity areas to improve the EOL experience, and a set of criteria and considerations for a dedicated EOL space. The process and opportunity areas to improve the EOL experience consisted of:

(1) privacy lights that indicate levels of privacy for families to staff while the families are experiencing a child's death;
(2) a comfort quilt used at time of death for staff to wrap the body in that would offer a softer experience for both staff and family;
(3) graphic "little reminders" around the hospital placed in strategic locations that would empower parents to be advocates for their child and remind staff to take a moment for mindfulness and mental health;
(4) announcement and spiritual lighting to make the walk to the morgue more comfortable for all stakeholders; and
(5) a remembrance garden that would act as a public/private space for staff and family to find moments of solace and peace while at the hospital and serve as a memorial space for children who died at the hospital.

Privacy Lights

The notion of privacy lights arose from discussions with parents who strongly felt that they lacked adequate privacy during difficult times (see **Figure 1, Supplemental Digital Content 1**, *http://links.lww.com/PQ9/A194*). These lights would be placed both inside and outside the patient room and set on a timer in 10- to 150minute increments. Different colors could signal different needs: lavender may be used for EOL care, whereas teal might indicate the need for general privacy. This system is superior to the current model, in which a handmade sign is placed on the door when a parent or patient requests privacy, as staff largely ignore these signs. Most staff assume that their needs to enter the room to provide care supersede the family's need for privacy. There is no standardized system for how long a sign stays up or who removes them, and because they are so frequently posted, clinical

Table 1. Conceptual Ideas for Process Improvement Opportunities

Conceptual Idea	Purpose
Messages and notes given to families or located through the hospital	To remind families and staff to ask important questions or take time for themselves
In-room tablets	To provide a platform for parents to research questions they may have, receive updates on their child's care, or provide them with a schedule for their day with names of clinical staff they may be interacting with throughout the day
The use of signals (cards and lighting) and infrastructure (windows and doorknobs)	To communicate family and patient needs of privacy or information
Staff and family discussion prompts	To help facilitate discussions around family needs for staff inexperienced with the EOL process
A projector within the patient rooms	To display images or curated scenes to provide a personalized environment for patient and families
Memory-making cards with topics and prompts	To engage with families to learn more about each other during this tough time (ie for children of certain ages, prompts may include "Favorite Color" or "Favorite Animal")
A Child Life cart	To assist Child Life Services for organizing their memory-making activities
An improved fabric cover for the medical gurney	To provide warmth and privacy of the child's body while being transported to the morgue
An adjustable feature to the medical gurney	To assist clinical staff when transferring the body from the ICU beds to the gurney for transport to the morgue
A patient quilt	To soften the transfer of the body from the ICU bed to the medical gurney before transport to the morgue
Symbolic messages and images on the pathway from the ICUs to the morgue	To comfort families and staff as bodies are transported
A lighting system within the staff corridor leading to the morgue	To notify staff of an approaching family or staff transporting a body to the morgue

staff participants described "alarm fatigue" with them. Potential barriers for successful implementation of placing privacy lights within line of staff sight; the simplicity of use; appropriate hue to evoke comfort rather than anxiety or confusion for families and staff; ease of maintenance; and habitat adoption by families and staff.

Comfort Quilts

Comfort quilts are a tool to enhance EOL care for staff, and as a memento for families. The current process is that after death, a shroud or plastic body bag contains the child's body for transfer to the morgue. The plastic is cold and sterile, and staff noted how difficult it is to place children inside. The comfort quilt can be given to the family at any time before the child dies or introduced after death if necessary, placed over the shroud for transfer, and transition with the child to the funeral home. Potential barriers for successful implementation of the comfort quilt included a resource sustaining method for creation, logistics for dissemination across the hospital, and planning of when to offer and deliver it to families.

Little Reminders

"Little reminders" may be placed strategically around the hospital. These cards, reading, for example, "Be an advocate for your child," are intended to empower families to regain some control by maintaining self-care and advocating for their child. They also remind staff to maintain self-awareness and mindfulness during stressful times. These reminders could take the form of signs in the elevator, at hand-washing stations, cafeteria napkin dispensers, or coffee cup sleeves. Potential barriers for successful implementation of "Little Reminders" included ensuring all messages and designs are approved through hospital administration, the upkeep and changing of signs across the hospital to keep a consistent cycle of new messages and the potential for staff or families spending large amounts of time at the hospital to background messages.

Automated Lighting

The current path from the pediatric ICU setting to the morgue is stark and industrial. Staff entering and exiting the hospital also utilize this hallway. There is no standardized process to announce that a procession is moving a child's body to the morgue. The fourth process improvement was an announcement lighting system that added warmth to the journey and improved staff awareness of a procession. The automated system, placed at the eye level, could be activated by a chaplain's badge or ID tag located on the transport cart such that it only activates at the correct time. The lighting could include a specific color system (lavender, for example) to ensure consistency with other areas of the hospital, or may consist of images of a spiritual avatar or animal meaningful to the child or family that progresses ahead of or alongside the cart (**see Figure 2, Supplemental Digital Content 2,** *http://links.lww.com/PQ9/A194)*. This system would make other hospital staff aware of the need to stand aside, respectfully and quietly, as the procession passed. Potential barriers for a successful implementation of this lighting system included the infrastructure of the hallways having the ability to support the lighting system, the cost of the lighting system to install and place, and the habit adoption by staff to use and recognize the meaning of the lighting system.

Remembrance Garden

This institution lacks a remembrance garden to memorialize children who have died and to provide staff and families with a space to grieve. Considerations of this space included public-facing, allowing families to visit at any time, and providing an opportunity for private contributions allowing staff or families to provide a legacy to a decedent child privately. Potential barriers for successful implementation of the garden included cost, location within the institution's campus, and the potential stigma in symbolizing death within the institution.

Dedicated EOL Space

Finally, team members designed a dedicated inpatient EOL space for children and families. Features would include an ample living room for family members to gather, a patient room connected by French doors, large windows allow natural lighting, and outdoor space to enable death or visitation outside when desired (**see Figure 3, Supplemental Digital Content 3,** *http://links. lww.com/PQ9/A194*). The area would include amenities for families and a soothing color palette with soft finishes. Parents preferred colors and finish materials that reminded them of nature: soft and soothing light blues, greens, and purples and warm, natural finishes of wood tones, to differentiate the space from clinically-focused areas of the hospital (**see Figure 4, Supplemental Digital Content 4,** *http://links.lww.com/PQ9/A194*). The design also emphasized access to amenities, such as toothbrushes, water, snacks, and coffee.[3]

DISCUSSION

Health "care" normally means "cure." When this is impossible, care means comfort.[19] In pediatric healthcare, care of the whole family is normative. Care, as comfort for a dying child and their family, mitigates poor outcomes for the parents and prepares them to grieve well. Perimortem and postmortem space influence parental emotional functioning. We describe the design process undertaken to improve parental and staff perimortem experience in a pediatric hospital. This process led to the description of 5 actionable process improvement opportunities, and the development of a low-fidelity prototype for each. The process additionally resulted in defining the criteria for a dedicated EOL space to inform future renovation or construction planning. This project presents the novel application of Craig and Vogel's design thinking as a method of addressing the need for quality improvement in pediatric

EOL care. Their method provided a structured framework with which to gather and understand data. One of the benefits of this process was the breadth of knowledge that was sought. Persons not generally accessed for participation in research studies (eg, bereaved parents, protective services, and interpreters) vetted the intervention prototypes to improve EOL care at this institution. The specific endproducts may not be generalizable. However, the development process is generalizable and replicable in any setting. The results are strengthened by the diversity of participants, which included representation from the numerous roles that influence the EOL process. Future directions include the engagement by hospital development representatives to seek donors to fund individual aspects of this project.

DISCLOSURE

ACKNOWLEDGMENTS

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