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Maintaining Integrity: How Nurses Navigate Boundaries in Pediatric Palliative Care

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ABSTRACT

Purpose: To explore how nurses manage personal and professional boundaries in caring for seriously ill children and their families.
Design and methods: Using a constructivist grounded theory approach, a convenience sample of 18 registered nurses from four practice sites was interviewed using a semi-structured interview guide.
Results: Nurses across the sites engaged in a process of *maintaining integrity* whereby they integrated two competing, yet essential, aspects of their nursing role – *behaving professionally* and *connecting personally*. When skillful in both aspects, nurses were satisfied that they provided high-quality, family-centered care to children and families within a clearly defined therapeutic relationship. At times, tension existed between these two aspects and nurses attempted to *mitigate the tension*. Unsuccessful mitigation attempts led to *compromised integrity* characterized by specific behavioral and emotional indicators. Successfully mitigating the tension with strategies that prioritized their own needs and healing, nurses eventually *restored integrity*. Maintaining integrity involved a continuous effort to preserve completeness of both oneself and one's nursing practice.
Conclusions: Study findings provide a theoretical conceptualization to describe the process nurses use in navigating boundaries and contribute to an understanding for how this specialized area of care impacts health care providers.
Practice Implications: Work environments can better address the challenges of navigating boundaries through offering resources and support for nurses' emotional responses to caring for seriously ill children. Future research can further refine and expand the theoretical conceptualization of *maintaining integrity* presented in this paper and its potential applicability to other nursing specialties.

Pediatric palliative care (PPC) is an approach to care that emphasizes providing comprehensive care to children with life-threatening conditions and their families (American Academy of Pediatrics [AAP], 2013). In Western nations, children in need of PPC are diagnosed with life-threatening illnesses, such as congenital disorders, progressive chronic conditions, or acute, serious illnesses that may place a child at risk for premature death (Dahlin, 2013). These children are cared for in a variety of settings, most frequently in oncology and intensive care units, and in families' homes and children's hospices. Consequently, registered nurses in these settings must attend not only to children's physical and medical needs, but also to their and their families' emotional, psychosocial, and spiritual needs.

Families of seriously ill children strongly desire and deeply appreciate genuine emotional support and empathic communication from health-care providers, especially at the end of life and after their child's death (Contro, Larson, Scofield, Sourkes, & Cohen, 2002; Davies, Larson, Contro, & Cabrera, 2011; Price, Jordan, Prior, & Parkes, 2011; Stevenson, Achille, & Lugasi, 2013; Weidner et al., 2011). Moreover, families report a higher quality of care when they receive emotional support and individualized attention from health care providers caring for their child at the end of life (Heller & Solomon, 2005; Macdonald et al., 2005). Nurses caring for children at the end of life experience sadness and grief, but offering emotional support to families is an essential aspect of their practice from which they derive meaning and work satisfaction (Bloomer, O'Connor, Copnell, & Endacott, 2015; Cook et al., 2012; Kain, 2013; Reid, 2013; Stayer, 2016). It is to be expected that nurses who practice in these emotionally charged situations confront issues related to

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professional boundaries but little is known about how nurses manage professional and personal boundaries within the context of PPC. The purpose of this paper is to describe how pediatric nurses defined boundaries and present a theoretical conceptualization of an identified process for managing boundaries, entitled maintaining integrity.

Background

Nurses offer emotional support to patients and families by establishing a therapeutic relationship, defined as "one that allows nurses to apply their professional knowledge, skills, abilities, and experiences towards meeting the health needs of the patient" (The National Council of State Boards of Nursing [NCSBN], 2014, p. 3). The therapeutic relationship occurs along a continuum of professional boundaries which are "the spaces between the nurse's power and the patient's vulnerability and which exists between the extreme ends of under and over-involvement (NCSBN, 2014, p. 3). The NCSBN advises nurses that boundary violations primarily occur in the over-involved end on the continuum when the nurse's needs supersede the patient's or the family's needs, such as when discussing intimate or personal issues with a patient, spending more time than necessary with a particular patient, or showing favoritism. Aligned with the NCSBN's guidelines, some authors caution nurses not to get too close, emotionally attached, or over-involved with patients and their families (Anewalt, 2009; Pate & Barshay, 2012; Roberts, Fenton, & Barnard, 2015). However, none of these guidelines describe how nurses themselves perceive and manage boundaries. That is, what do "spaces between the nurse's power and the patient's vulnerability" look like in actual day-to-day practice?

Pediatric nurses, in a phenomenological study exploring therapeutic boundaries (Totka, 1996), experienced an intrapersonal struggle in finding an appropriate level of involvement with families. The research team wrestled with identifying the point when instances of over-involvement became "crossing the line" because sometimes families and nurses mutually benefitted from over-involvement. Similarly, other researchers (Cook et al., 2012; Reid, 2013) reported that nurses caring for dying children defined boundaries by their level of involvement with families and acknowledged that over-involvement periodically occurred; they too were challenged in maintaining the fine line between involvement and detachment. These studies suggest that professional boundaries are more complex and layered with nuances than current NCSBN (2014) guidelines indicate.

Other reports of nurses caring for seriously ill or dying children contributed to an understanding of the emotional, more personal, aspects of nurses' work. Working with seriously ill or dying children triggered nurses' reflections about their personal assumptions and beliefs about self, life, death, past unresolved losses, future anticipated losses of loved ones, and loss of self through death (Papadatou & Bellali, 2002; Yam, Rossiter, & Cheung, 2001). Nurses responded to patients' deaths with grief, sadness, hurting, moral distress, struggling and suffering. These elicited emotions can lead to compassion fatigue, which is state of feeling physically, emotionally, and mentally exhausted to provide adequate nursing care (Berger, Polivka, Smoot, & Owens, 2015). Burnout is a component of compassion fatigue and associated with nurses' grief experience and work satisfaction (Adwan, 2014; Meyer, Li, Klaristenfeld, & Gold, 2015). Burnout can also result from moral distress (Rushton, Kaszniak, & Halifax, 2013), which is provoked by emotionally-wrought situations, such as aggressive treatments that are against the patient's best interest or flawed interdisciplinary communication (Trotochaud, Coleman, Krawiecki, & McCracken, 2015). Moreover, emotional responses can persist, such as memories of patients' deaths continuing to "haunt" nurses years after the experience (Papadatou & Bellali, 2002; Rashotte, Fothergill-Bourbonnais, & Chamberlain, 1997). Olson et al. (1998) reported that pediatric oncology nurses openly wept when recounting their lowest point, or nadir experience, even when these instances happened many years earlier. Caring for seriously ill children who may die affects pediatric nurses on a personal level. Understanding how nurses manage professional boundaries must also include examining their personal boundaries, thus the overall aim of our study was to explore how nurses perceived and managed professional and personal boundaries. In this paper, we describe how pediatric nurses defined boundaries and present a theoretical conceptualization of how the nurses engaged in a process of maintaining integrity to manage boundaries.

Design and Methods

Because little was known about how pediatric nurses manage professional and personal boundaries, we selected a qualitative research design, specifically grounded theory (GT). GT focuses on processes and enables development of a theory or theoretical conceptualization grounded in participants' own words, experiences, and descriptions (Charmaz, 2014). Approval to conduct the study was obtained from the institutional review boards at the major university with which the researchers were affiliated and at each study site.

Recruitment

To enhance sampling variation, the principal investigator (PI) recruited registered nurses (RNs) from two sites: a freestanding pediatric palliative care center and an academic tertiary-care children's hospital, both situated in a large, metropolitan area in the Western United States. The nine-bed center is independent from a hospital and offers respite, transitional, and end-of-life care to children with life-threatening conditions. In the children's hospital, nurses were recruited from the three units where the most deaths occur (Institute of Medicine [IOM], 2003): the oncology unit, intensive care nursery (ICN), and pediatric intensive care unit (PICU).

Using purposeful sampling, RNs were recruited through approved flyers posted in each setting and through snowball sampling. The inclusion criterion was that participants were employed as RNs in one of the four study settings. Interested RNs emailed or phoned the PI to schedule a mutually convenient time and place to meet for an interview, most often in a private area at their workplace before or after their shift. Consent, along with demographic data, was obtained at this time. Following the Consolidated Criteria for Reporting Qualitative Studies (COREQ), the female PI, interviewed all participants following training in qualitative methodologies, specifically grounded theory (Tong, Sainsbury, & Craig, 2007). The PI is an RN and established a relationship with the four study sites prior to participant enrollment through introducing the study and its purpose at staff meetings. The PI had previously worked as an RN on one of the sites prior to the study, which prompted an interest in this study area.

Data Collection

The sample included 18 RNs (10 from the PPC center, 3 from the oncology unit, 3 from the ICN, and 2 from the PICU). The participants were predominantly female (89%), White (83%), with an overall average age of 39 years. Nearly all (84%) had a BS or MS, had worked in their respective settings for an average of nearly 4 years, and their years of nursing experience ranged from 2.5 to 44 years with a mean of nearly 16 years (see Table 1). Although two males (11%) completed interviews, we refer to all participants by the female gender to maintain participant anonymity. The PI conducted interviews using a semi-structured guide with open-ended questions. To set a comfortable tone, all interviews started with a neutral prompt: "Tell me about how you came to work here." Other sample questions included: "When you tell others of your job, what do you tell them?", "Describe a family or child you cared for that stands out in your memory and tell me the story of caring for them," and "Describe how you cope with the emotionally stressful part of your job." Interviews ranged from 45 to 75 min, were audiotaped, and transcribed verbatim by a professional transcription