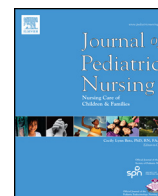




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## Nurses' Experiences of End-of-life Photography in NICU Bereavement Support

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## ABSTRACT

**Purpose:** To qualitatively explore neonatal intensive care nurses' experiences with end-of-life photography as part of their bereavement support work with families.**Design and Methods:** An Interpretive Phenomenological Analysis with data collected through a focus group ( $n = 6$ ) and one semi-structured interview ( $n = 1$ ) with neonatal nurses from a Level 3/4 NICU in a Canadian pediatric hospital.**Results:** Participants' comfort with EOL photography developed over time through exposure to bereavement scenarios and positive experiences with families. Participants experienced a feeling of pressure to balance the photography with clinical responsibilities and find the right time to introduce photography while being sensitive to family experiences. Participants experienced EOL photography as something tangible to give families and were satisfied knowing the images might play an important role in the family's healing after the NICU.**Conclusions:** All participants had come to value EOL photography as a positive and meaningful part of their work with bereaved families. Identified challenges related to balancing the practice with the unpredictable flow and demands of critical care and to developing an appreciation for and comfort with the photography as part of their healing and the families' healing.**Practical Implications:** Findings contribute insight into care-provider experience that can inform best practices, training, and staff support for palliative and bereavement work in neonatal and pediatric settings. The findings suggest a need to support nurses emotionally and clinically in carrying out this photography as part of their care for families.

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## Introduction

The majority of newborn deaths in developing countries occur in tertiary Neonatal Intensive Care Units (NICUs) (Lam, Kain, Joynt, & VanManen, 2016). Over the last many decades, there has been an increasing amount of research into what hospitals should be offering families in terms of palliative care and bereavement support at the end of an infant's life (Gold, Dalton, & Schwenk, 2007; Harvey, Snowdon, & Elbourne, 2008; Mills et al., 2014). In this research, photography consistently appears as a best practice that families value immensely and that should be available as a means of incorporating memory-making into the end-of-life experience (Blood & Cacciatore, 2014; Kenner, Press, & Ryan, 2015; Martel & Ives-Baine, 2014; Williams, Munson, Zupancic, & Kirpalani, 2008). Having nurses or other staff encourage families to take photos during their time with their newborns or offer to take

photos for them is largely understood as part of compassionate care in NICU environments where families are welcomed to spend time with their baby and gather or create mementoes to take home with them (Ives-Baine et al., 2013; Laing & Freer, 2008; Limbo & Kobler, 2010).

As bed-side care-providers, nurses frequently build close relationships with the families in their care and play a key role in bereavement support (Catlin & Carter, 2002; Fegren & Helseth, 2009; Gale & Brooks, 2006; Thibeau & Naquin, 2012). Due to this emotional and practical proximity, nursing staff are also heavily involved in facilitating end-of-life (EOL) photography in the NICU. Working alongside social workers, medical photographers, and other staff members, nurses are often the team members who introduce the idea of photography to families as part of the transition to end-of-life care and who take photos for families during their stay. While often termed 'bereavement photography' or 'post-mortem photography,' we use the term 'end-of-life photography' with a few intentions. For the purposes of this research, we consider EOL photographs to be any photos taken across a newborn's short life, through to their final moments with their families, and/or shortly after they die. This photography is situated within contemporary neonatal end-of-life practices, which typically includes validation of parental grief, acknowledgement and celebration of life, and the facilitation of

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ritual and legacy creation within the hospital setting (Levick, Fannon, Bodermann, & Munch, 2017; Limbo & Kobler, 2010). This end-of-life care paradigm gives photography its clinical rationale and its cultural sensibility.

Neonatal EOL photography is unique in that it is one of the few photographic practices today that invites the camera—now also built into highly accessible and mobile tablets and smart phones—into a healthcare space to document end-of-life moments. This aspect of EOL photography makes it an incredibly sensitive practice and it should not be assumed that all care-providers will be immediately comfortable taking the photos or introducing the idea to families. In addition to understanding how families experience having photos taken as part of their time in the NICU, it is equally important to understand how nurses experience this photography as part of their work in supporting families through the dying and death of a newborn. Building on others' explorations into the end-of-life experiences of NICU care providers (Bloomer, O'Connor, Copnell, & Endacott, 2015; Green, Derbyshire, Adams, & Jackson, 2016; Ives-Baine et al., 2013; Kain, 2013; Lindsay, Cross, & Ives-Baine, 2012; Warren, 2017), gaining insight into how nurses make meaning of EOL photography as clinical, creative, and emotional work may help in developing best practices for training and policy. It is crucial that care-providers feel supported in this aspect of their work so they in turn feel comfortable and confident when supporting families bereaved by the death of their baby.

## Purpose

This research was guided by the following question: *How do nurses experience and make meaning of EOL photography within the NICU environment as part of their nursing work with families bereaved by the death of their newborns?* The purpose of this inductive study was to contribute qualitative insights into these experiences to inform best practices in bereavement support and staff support in NICU settings.

## Methods

### Research Ethics

Researchers obtained full approval by the Research Ethics Board at the research setting and the Office of Research Ethics at the researcher's (SM) university prior to the study's commencement. All participants gave informed consent and, due to the potentially sensitive nature of the topic, were provided a list of support resources prior to starting the discussion. All participants were given the option of meeting off-site if they preferred, but all were comfortable with conducting the focus group and interview on site at their workplace.

### Research Setting and Recruitment

The research setting was a Level 3/4 NICU at a Canadian pediatric hospital with a long-standing practice of offering end-of-life photography as part of their standard of care. Recruitment took place through a letter posted in the NICU staff room and emailed from the NICUs Palliative Care and Bereavement Coordinator to all part-time and full-time nurses who were currently employed in the NICU ( $n = 150$ ). Inclusion in the study required participants to have worked in the NICU for at least two years and to have taken EOL photos at least twice preceding the interview.

### Methodology

The study was designed as an Interpretive Phenomenological Analysis (IPA), which is a qualitative framework for understanding how people make meaning of their lived experience (Benner, 1994; Smith, Flowers, & Larkin, 2009; Smith, Harré, & Van Langenhove, 1995). The phenomenological elements of the study were informed by the

philosophy of Maurice Merleau-Ponty (1962, 1964, 1969), aligning conceptually with other qualitative health research that draws on Merleau-Ponty's work to explore the "lived-body's" experience of the "life-world" (e.g. Dahlberg, 2011; Lundgren, 2011; Murray & Holmes, 2014; Schuster, 2013; Wynn, 2002). For the purposes of this study, the IPA framework informed: the inductive research question focused on experience and meaning-making; the noting of tone and gesture in addition to spoken word in data collection and analysis; the level of immersion during analysis; and a double hermeneutic process in which the researchers engaged the participants in the interpretation of their lived experiences, then interpreted that interpretation through immersive analysis of their language, speech, and gestures (Smith & Osborn, 2008).

### Data Collection

Data were collected through one focus group ( $n = 6$ ) and one semi-structured interview ( $n = 1$ ). The interview was conducted with a participant who was not able to join the focus group due to a scheduling conflict. All scheduling was based on participant convenience and availability, keeping in mind the challenges posed by shift work. The interview was conducted by one researcher (SM). The focus group was conducted by the same researcher with the help of an experienced note-taker who recorded who was speaking, key points from each speaker, and reflections on the tone or gestures throughout the conversation. The researcher also made memos throughout the conversation, particularly around the embodied aspects of dialogue and interaction that might not be captured through audio recording. The same open-ended questions were asked in both the focus group and the interview and focused on the nurses' experience taking the photos, their experience with families, and their experience with the photography and the images themselves. The focus group and the interview were both approximately one hour long, and were audio recorded and later de-identified and transcribed.

### Data Analysis

Analysis was carried out through a series of steps typical of IPA, designed to immerse the researcher in the data for close interpretation of the meaning expressed by the participant (Smith et al., 2009; Smith & Osborn, 2008):

- Listening to each interview and annotating for overall impression of the dialogue
- Open coding significant points of dialogue in one margin
- Cross-referencing transcript annotations with field notes
- Reading each transcript, noting possible theme titles in the other margin
- Micro-analysis of language, highlighting words or phrases in the document
- Clustering connected themes as superordinate theme
- Axial coding, allowing new themes to emerge, noting patterns and divergences as meaningful

The open coding and micro-analysis was completed by one researcher (SM), then the thematic clustering and axial coding was completed by both researchers (SM and LIB). In line with a phenomenological approach, the analytic process was designed not to achieve consensus but to achieve coherence across the data and the two researchers' interpretation of the meaning in the data (Smith, 2004). As such, differences were noted and synthesized through a face-to-face discussion between the researchers. A summary of initial findings was also shared with participants for validation and no discrepancies were reported.

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