



Caring for Children Who Die Unexpectedly: Patterns That Emerge Out of Chaos

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Despite medical advances in technology, improved socioeconomics, and medical knowledge, an estimated 55,000 children die every year in the United States. A phenomenological study was conducted at a tertiary-quaternary children's hospital to determine the emerging patterns amidst the chaos with nurses caring for children dying unexpectedly. Implications for nursing practice include a progression of caring, a set of patterns that emerge out of the seeming chaos of a coding patient. These patterns shed light on the interactive relationships within the hospital and can foster collaboration among bedside nurses, advanced practice nurses, inter-professional team members, directors, and hospital administrators.

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CHILDHOOD DEATHS IN the United States have been reduced by advances in technology, socioeconomics, public health, and improving medical therapies. Despite these advances, according to the American Academy of Pediatrics and the Institute of Medicine, approximately 55,000 children aged 0 to 19 years die annually from congenital conditions, accidental and non-accidental trauma, severe infection, cancer, or drowning; most of these deaths occur in the hospital (Field & Behrman, 2003; Nelson, 2000). In contrast, 100 years ago children usually died at home when “death in infancy and early childhood was frequent and there were few families who didn't lose a member of the family at an early age” (Kubler-Ross, 1969, p. 15). There are *expected* deaths, where a child has been sick for an extended period of time with something like cancer or muscular dystrophy, and there are *unexpected* deaths due to trauma, drowning, or an illness like meningococemia.

When nurses first started identifying a need for special training to care for dying children, they found a reported shortage of theoretical information to enlighten the practice (Davies et al., 1996). Designing a study that captures the

essence of what a pediatric intensive care unit (PICU) nurse accomplishes on a daily basis while caring for a dying child is a research challenge. The purpose of this study was to explore the lived experience of pediatric intensive care nurses caring for dying children in a tertiary-quaternary facility (Meyer, 2011).

Conceptual Definitions

Care

The use of the concept of care and caring related to nursing needs to be defined for this research because they both have so many meanings. Care begins with a response for the well-being of another person who may be in a vulnerable situation or in need (Meyer, 2011). Care is the root of the verb caring.

Caring

Caring as a concept has been described numerous ways in the nursing literature, including as a way to provide support, helping someone establish self-fulfillment, a human trait, a

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moral ideal and imperative, interpersonal and therapeutic, and the art of nursing (Spichiger, Wallhagen, & Benner, 2005; Watson, 1985; Widerquist & Davidhizar, 1994). The concept of caring has different perspectives; however, caring has been proposed by some nursing theorists to be a central component of the nursing profession because it transcends language, customs, and cultural differences and is universal (Rexroth & Davidhizar, 2003; Watson, 1985; Watson & Smith, 2002).

Dying

The definition of dying can be misleading in today's healthcare system. As finite beings, people are all destined to die eventually; however, the culture makes every effort to prolong that moment in time. Kubler-Ross (1997) viewed dying as a natural passage from life to death. Children in Western society are not expected to die prematurely. However, a significant number of children are admitted to the PICU who may be in danger of dying imminently and unexpectedly, while others may have many more years to live due to new palliative treatments and surgeries. Dying in Western medicine is often viewed as "dysfunctional conditions to be controlled by science" (Papadatou, 2009, p. 5).

Literature Review

Death of a child can "...challenge the familiar and cherished assumptions through which we make sense of the world..." (Papadatou, 2009, p. 137). Nurses caring for dying children in the PICU are faced with the noise of the busy environment and may be concentrating on the tasks of using the equipment as a way to cope with the anxieties involving death. They may have feelings of fear and hopelessness as they hold a hand or listen to a question (Papadatou, Bellali, Papazoglou, & Petraki, 2002). Paradoxically, they may think of death as the great transition, similar to the experience of birth, and see themselves as co-creators of meaning in the experience. In the midst of this chaos and crisis situation, the members of the inter-professional team respond to the situation, collaborating and creating patterns of energy within the organization (Crowell, 2011).

There are different types of patients cared for in the PICU: those who are acutely ill but will get better with curative technological and medical intervention. There are those who are chronically ill with life-limiting disease, receive both curative treatment and palliative treatment/therapies simultaneously, and may come in and out of the hospital numerous times throughout their lifespan in various degrees of illness. Finally there are those who are dying imminently, where curative treatment may be tried and fails (Meyer, 2011).

Kubler-Ross is well known for her seminal work to improve the care of dying patients with her published works

in which she presented the five stages of dying, perspectives on caring for dying children, and her own journey facing death (Kubler-Ross, 1969; Kubler-Ross, 1983; Kubler-Ross, 1997). Jeanne Quint Benoliel was one of the first nurses in the United States to explore the issues regarding caring for dying patients (Benoliel, 1982; Davies et al., 1996; Papadatou, 2009).

The topic of caring for dying children is one with fewer published works. The main researchers with articles published about caring for dying children between 1996 and 2002 were Betty Davies, Judy Rashotte, and Danai Papadatou. In the last few years, more studies have been published related to caring for dying children; however, there are still a small number of research studies in this specialty area (Beckstrand, Rawle, Callister, & Mandleco, 2010). Critically ill children who may be dying are seen daily by nurses in the PICU. However, the patterns, structures, and effects of the lived experience are not well documented.

Methodology

Inductive studies that use a phenomenological methodology result in a description of the experience being examined (Brink & Wood, 1998). In this case, it was the experience of PICU nurses caring for dying children. Phenomenology consists of descriptions and is a way to view objects and events as they happen (Omery, Kasper, & Page, 1995). Using this method can establish a basis for further nursing knowledge development and more clearly define nursing practice because knowledge starts with experience within the world (Husserl, 1962). Phenomenology does not provide a theory to explain the world; instead, it provides a way to gain possible insights into the world (Van Manen, 1990). It is important to establish where nursing knowledge originates and present the case for using phenomenology. In her seminal work, Barbara Carper analyzed the patterns, forms, and structure inherent in nursing practice up to that time. She said, "The body of knowledge that serves as the rationale for nursing practice has patterns, forms, and structure that serve as horizons of expectations and exemplify characteristic ways of thinking about phenomena" (Carper, 1978, p. 13).

A minimum of 10 nurses was determined to be adequate for the study utilizing purposive sampling to ensure participants could provide knowledgeable descriptions about the experience (Burns & Grove, 2001; Burns & Grove, 2009; Speziale & Carpenter, 2007). A flyer was posted in the PICU with the permission of the director and the recruitment information was also placed in the unit newsletter. The researcher was known by the PICU nurses to be recruiting for inclusion in a research study. Inclusion criteria for this study were: (a) participants currently working as PICU nurses; (b)

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