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Recommended Citation

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A Concept Analysis of Parental Uncertainty in Illness of an Infant

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Abstract

Background:

The concept of uncertainty in illness has been well described and applied to many different areas of nursing and other disciplines. Specifically, parental uncertainty in illness of an infant is a meaningful concept that has specific attributes and implications. A current concept analysis that considers the changing healthcare setting, historical conceptual inconsistencies, and a lack of information concerning parents of infants is needed.

Purpose:

To identify essential antecedents, attributes, and consequences of parental uncertainty in illness using Rodgers' Evolutionary Concept Analysis method.

Methods:

A literature search was conducted using PubMed, CINAHL, and PsycInfo. The following keywords were used in combination using the Boolean terms "AND" and "OR": parental uncertainty; infants; parental uncertainty in illness; preterm infants; parent; uncertainty. Inclusion criteria: articles published between 2000 and 2017 and published in English. The search included 38 articles published from 2000 to 2017 with a specific focus on parental uncertainty in illness.

Findings:

Parental uncertainty in illness of an infant is a paradoxical, cognitive, and emotional experience in which there is an inability to create meaning and may cause disruption in parental role development.

Implications for Practice:

Nursing care of parents with ill infants and children must include sensitivity to parents' experiences of uncertainty in illness. Nurses are uniquely positioned to normalize parental uncertainty and facilitate healthy coping.

Keywords

Concept analysis, Infant, Neonatal intensive care, Parents; Uncertainty

The concept of uncertainty in illness has been well described and applied to many areas of nursing and other disciplines. Uncertainty is central to the illness experience and it is from this uncertainty that all activities related to healthcare are motivated (Han, Klein, & Arora, 2011). Florence Nightingale wrote about uncertainty in "Notes on Nursing" in 1895 saying, "Apprehension, uncertainty, waiting, exception, fear of surprise, do a patient more harm than any exertion" (Nightingale, 1992, p. 22).

Parents' descriptions of having an infant in the neonatal intensive care unit (NICU) vary. Some described their experiences as stressful, depressing, disappointing, and with a loss of control (Obeidat, Bond, & Callister, 2009). Others reported feelings of gratitude, optimism and hope, even in the face of death or disability for their child (Arnolds, Xu, Hughes, McCoy, & Meadow, 2018). Few researchers have focused specifically on the parental experience of uncertainty in illness of an infant. Therefore, nurses often turn to the literature on uncertainty in illness of pediatric patients to find the nuanced differences between uncertainty in the pediatric and infant populations.

Nurses use the practice of concept analyses to help examine and describe the fundamental components that are central to their discipline. Concept analyses offer meaningful definitions that help describe relationships and application to nursing practice (Rodgers & Knafel, 2000). Helping clinicians and researchers to fully describe parental uncertainty of illness in infants allows nurses to conduct a comprehensive assessment of parental needs and then develop interventions to help parents cope with the uncertainty of having a sick or premature infant.

Background

Changes and advancements in technology and practice standards have increased survival rates of extremely preterm infants over the last 20 years. Thus, the environment in which parents of sick or premature infants are being asked to make healthcare decisions is different than it was 20 years ago, which may contribute to more uncertainty. Parents have described experiencing uncertainty during the entire duration of having an ill child and when survival is uncertain. This uncertainty permeates through attaining diagnoses, adjusting to complex treatments, achieving confidence as a parent, and optimizing quality of life for all family members (Alvesson, Lindelow, Khanthaphat, & Laflamme, 2013; Carpentier, Mullins, Chaney, & Wagner, 2006).

Methods

The concept of parental uncertainty is dynamic and cyclic in nature and thus the tool used to evaluate and define it must also provide for these qualities. Rodger's seven-step evolutionary method is the most appropriate method for concept analysis in this instance as it is a reexamination of a concept that has been defined in the past. Significant components of Rodger's evolutionary method include identification of the following: the concept of interest; surrogate terms; realm for data collection; attributes of the concept; references; antecedents and consequences of the concept; related concepts; and a model case of the concept (Rodgers, 1989). The purpose of this analysis is to reexamine the concept of uncertainty in illness of an infant. Although this is not a new concept, technologies have changed, illness trajectories have been altered, and the age of viability continues to be modified. Nurses need an updated concept analysis of parental uncertainty in illness of an infant to holistically care for infants and families.

Search Strategy

There are several definitions of uncertainty in illness reported in the literature. One example is a multidimensional concept that is a neutral cognitive state and not an emotional outcome (McCormick, 2002). Another is that it is a dynamic state in which there is an inability to assign possibilities for outcomes (Penrod, 2001). Surrogate and related terms identified include: unpredictability, inconsistency, stress, hope, and distress (Arnolds et al., 2018; Chaney et al., 2016; Holm et al., 2008). A literature search was conducted using the following databases: PubMed, CINAHL, and PsycInfo. The following keywords were used in combination using the Boolean terms "AND" and "OR": parental uncertainty; infants; parental uncertainty in illness; preterm infants; parent; uncertainty. Inclusion criteria included: articles published between 2000 and 2017 and articles published in English. The years searched was chosen as the last comprehensive review that examined the concept of illness uncertainty in parents was published in 2000 (Stewart & Mishel, 2000). Exclusion criteria included: opinion articles; book chapters and books; and articles in which the concept of interest was something other than uncertainty in illness or parental uncertainty of a child's illness. Forty-two articles were identified after duplicates were removed; 38 articles were included in the final analysis. See [Figure 1](#) for a flow diagram of the literature search. See Table 1 for a detailed summary of reviewed literature (Supplemental Digital Content, <http://links.lww.com/MCN/A52>).

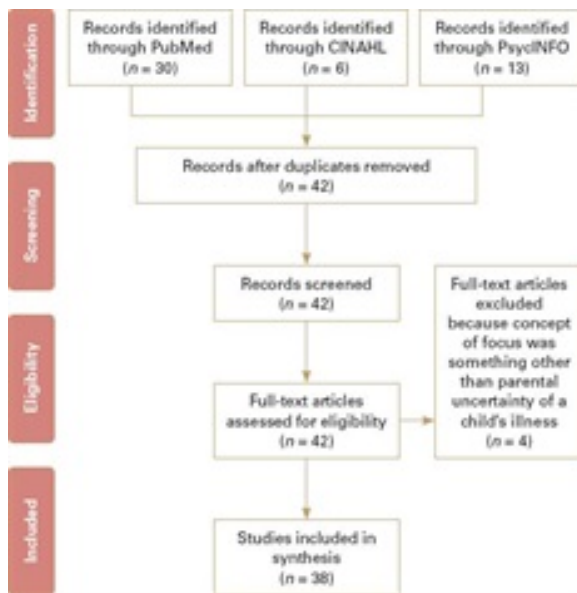


FIGURE 1.: Flow Diagram of Article Search and Selection Process

Data Analysis

During the data analysis phase, themes are identified and labels are created through inductive reasoning. Conclusions about themes and labels were broadly generated from the data (Rodgers & Knaf, 2000). This analysis led us to identify *parental uncertainty in illness of an infant* as the concept of interest, and not the broader concept of uncertainty in illness. This concept is described by its antecedents (a preceding event, condition, or cause); attributes (a quality, character, or characteristic ascribed to something) and consequences (something that is produced by a cause or necessarily following a set of conditions). See [Figure 2](#).



FIGURE 2.: Diagram of Antecedents, Attributes, and Consequences

Antecedents

Complexity in childhood illness, diagnosis, and management in multifaceted environments appears to be an antecedent to parental uncertainty in illness. The reciprocal influences of family, healthcare systems, and environment are often associated with the development of parental uncertainty (Shannon & Lee, 2008). Undiagnosed conditions and prognostic ambiguity are also examples of this complexity contributing to parents developing uncertainty (Chaney et al., 2016; Dodgson et al., 2000; Hayeems et al., 2017; Kerr & Haas, 2014; Tluczek, Mckechnie, & Lynam, 2010). The antecedent of *lack of meaning* is another theme in the literature (Santacroce, 2003). Parents of preterm infants experience a lack of meaning as a disruption and alteration in parental understanding of reality (Lasiuk, Comeau, & Newburn-Cook, 2013). *Ambiguity* is identified across all disciplines as an antecedent to describe parental uncertainty in illness (Nelson, Kirk, Caress, & Glenny,

2012; Tackett et al., 2016). Parents described this ambiguity as never feeling safe and as though their child's life is always at risk despite the passing of time (Tong, Lowe, Sainsbury, & Craig, 2008).

Attributes

The *paradoxical experience* of parental uncertainty in illness comes from the understanding that uncertainty may be perceived as a threat or an opportunity (Czuchta & McCay, 2001; Madeo, O'Brien, Bernhardt, & Biesecker, 2012). As an example of a threat, mothers of children with chronic health conditions experienced increased levels of psychological and physical symptoms (Holm et al., 2008). Conversely, parents of children with genetic conditions (Whitmarsh, Davis, Skinner, & Bailey, 2007) and parents of children with childhood multiple sclerosis (Hinton & Kirk, 2017) reported valuing uncertainty in their child's illness as representing future possibilities and fragile hope. Another attribute of parental uncertainty in illness is the experience as both *emotional and cognitive*. Fear, hopelessness, and feeling overwhelmed are examples of emotional attributes ascribed to parental uncertainty (Benedetti, Garanhani, & Sales, 2014; Bolívar Montes & Montalvo Prieto, 2016; Czuchta & McCay). Cognitive processing is involved with parental psychological adjustment and health behaviors (Page et al., 2012). Multiple authors discussed the *enduring* nature of parental uncertainty as an attribute (Håkstad, Obstfelder, & Øberg, 2016; Lin, Yeh, & Mishel, 2010; Santacroce, 2002; Truitt, Biesecker, Capone, Bailey, & Erby, 2012). The enduring quality of uncertainty was described by parents of premature infants for 3, 6, and 12 months corrected gestational age (Håkstad et al.).

Consequences

The need for parents to manage illness-related uncertainty was found across disciplines and often resulted in *information seeking behaviors*. Tluczek et al. (2010) reported that parents who received an equivocal diagnosis for cystic fibrosis on the newborn screen sought to reduce uncertainty through searching for information. Parents seek credible authorities to help reappraise their feelings of uncertainty (Kerr, Harrington, & Scott, 2019). *Alterations in parental role attainment* was uniquely a dominant consequence of uncertainty in illness focused on parents of neonates and infants (Lasiuk et al., 2013; Obas, Leal, Zegray, & Rennick, 2016; Santacroce, 2001). The typical transitions into parenthood were changed across many settings in this population. As an example, parents who experienced illness uncertainty and reliance on nurses to perform parental duties reported decreased parent–infant closeness and decreased attachment (Watson, 2011). *Coping* with uncertainty was also identified as a theme (He, You, Zheng, & Bi, 2016; Stratton, 2004; Zierhut & Bartels, 2012). Examples of coping include positive thinking, delaying worry, managing information, open communication, and hope (Truitt et al., 2012; Zierhut & Bartels).

Identification of a Model Case

The rich interviews of parents at home with their infant after discharge from the NICU described by White, Gilstrap, and Hull (2017) provide a model case of parental uncertainty in illness. The following quote from a mother after NICU discharge demonstrates feelings of uncertainty around the transition of becoming a parent (White et al., p. 109): *You are responsible for them. You have to worry...You are staring at them making sure they are breathing. It is so different. You are so used to other people worrying about that stuff for you. You are worried [in the NICU], but they are worried more because that's their job.*

Direction of Further Investigation

An evolutionary concept analysis identifies the direction of further investigation (Rodgers & Knaf, 2000). Research is needed on measurement of psychological and physiological responses to enduring in parental uncertainty to provide for a more comprehensive understanding of the experience of parental uncertainty in illness. More information explaining how parents and patients transition from emotional to cognitive management of uncertainty would be beneficial to provide a basis for developing associated nursing interventions.

Uncertainty in Illness in Parents of Infants

Twelve of the articles reviewed included a population of parents whose illness uncertainty was concerning their sick or premature infant. Although there is much to be learned about parental uncertainty in illness regardless of the age of the child, one must consider the probability that the uncertainty experienced by parents of sick or premature infants and consequences of their experiences may be uniquely different. For example, in this review researchers found for parents of sick or premature infants, the disruption in both parental role and family role is a consequence of uncertainty in illness (Obas et al., 2016; Santacroce, 2001). This role disruption is distinctively noted in the literature in parents of infants and is not identified as a theme in the greater body of literature. The disruption in parental role development is related to alterations in transitions that normally occur, such as feelings of belonging and parent–infant relationships (Granrud, Ludvigsen, & Andershed, 2014; Watson, 2011). Perhaps the unique experience of parental uncertainty in illness of an infant begins at the birth of a premature or sick infant and continues for months to years depending on the trajectory of the infant's health. More research with parents of a sick or premature infant would help nurses care providers further understand the concept.

Clinical Implications

The proposed definition of parental uncertainty in illness in an infant is: *a paradoxical, cognitive and emotional experience of parents with an ill infant, in which there is an inability to create meaning, and may cause disruption in parental role development*. Nurses should work to understand parents' perception of uncertainty. Nurses should provide evidence-based care to normalize parents' experiences of uncertainty and provide the support needed to facilitate coping and optimal parental interactions with their infants. The transition to parenthood is an important developmental step that may be altered as a result of uncertainty. Nurses are well equipped to help facilitate this role development in the face of uncertainty. Nursing interventions such as providing a healing environment, involving parents as partners in care of the infant, facilitating education, and offering therapeutic communication all help parents to become comfortable in their role as a parent. When parents have questions about the illness or status of their infant, information should be provided at the appropriate literacy level and in a language the parents understand. Offering established support services, such as palliative care as appropriate, to facilitate parental decision-making and parental role attainment may be beneficial. Referrals for outpatient care if needed should be part of planning for hospital discharge. More research is needed to fully conceptualize how parents experience uncertainty in illness of their infant, and how it impacts the continuum of childhood and family growth and development.

Suggested Clinical Nursing Implications

- Recognize the parental experience of uncertainty in illness of an infant when working with families in the NICU and offer support as parents cope with the consequences of uncertainty.
- Provide information about the illness to the parents in language they understand, and at the appropriate literacy level; use interpreters as needed.
- Providing a healing environment, involving parents as partners in care of the infant, facilitating education, and offering therapeutic communication all help parents to become comfortable in their role as a parent.
- Assess the parents' family and friend support networks.
- Acknowledge that parental uncertainty in illness is not an explicitly negative experience. Each parental experience is relative and requires unique attention and care planning.
- Use established services, such as palliative care if appropriate, to support parents through feelings of uncertainty about their sick or premature infant. Make sure the parents have referrals as needed when the infant is discharged.

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