7-2019

A Concept Analysis of Parental Uncertainty in Illness of an Infant

Kathryn J. Malin
Marquette University, kathryn.malin@marquette.edu

Teresa S. Johnson
University of Wisconsin - Milwaukee

MCN, The American Journal of Maternal/Child Nursing, Vol. 44, No. 4 (July/August 2019): 206-211. DOI.

A Concept Analysis of Parental Uncertainty in Illness of an Infant

Kathryn Jeanne Malin
The University of Wisconsin Milwaukee
Neonatal Nurse Practitioner, Children's Hospital of Wisconsin Milwaukee, Milwaukee, WI
Teresa S. Johnson
College of Nursing, The University of Wisconsin Milwaukee, Milwaukee, WI

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 & Knafl, 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).

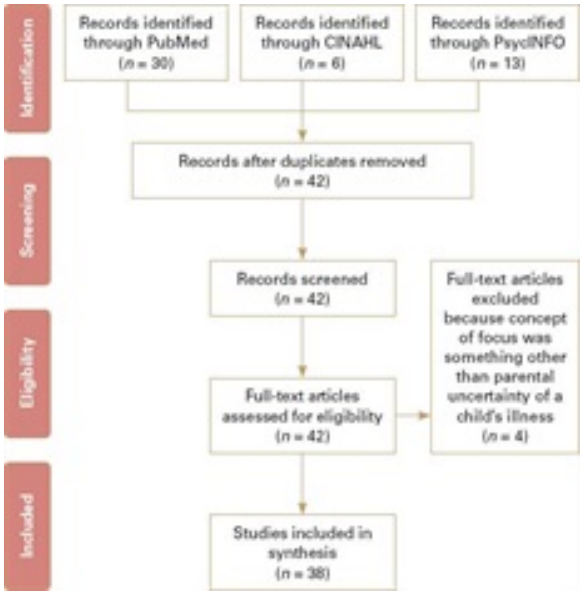

FIGURE 1.: Flow Diagram of Article Search and Selection Process

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 & Knafl, 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 & Knafl, 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.

References

Alvesson H. M., Lindelow M., Khanthaphat B., Laflamme L. (2013). Coping with uncertainty during healthcare-seeking in Lao PDR. *BMC International Health and Human Rights*, 13, 28. doi:10.1186/1472-698X-13-28

Arnolds M., Xu L., Hughes P., McCoy J., Meadow W. (2018). Worth a try? Describing the experiences of families during the course of care in the neonatal intensive care unit when the prognosis is poor. *Journal of Pediatrics*, 196, 116–122.e3. doi:10.1016/j.jpeds.2017.12.050

Benedetti G. M., Garanhani M. L., Sales C. A. (2014). The treatment of childhood cancer: Unveiling the experience of parents. *Revista Latino-Americana de Enfermagem*, 22(3), 425–431. doi:10.1590/0104-1169.3264.2433

Bolívar Montes L. A., Montalvo Prieto A. (2016). Uncertainty associated to parents of preterm infants hospitalized in neonatal intensive care units. Investigación y educación en enfermería, 34(2), 360–367. doi:10.1590/S0120-53072016000200016

Carpentier M. Y., Mullins L. L., Chaney J. M., Wagner J. L. (2006). The relationship of illness uncertainty and attributional style to long-term psychological distress in parents of children with type 1 diabetes mellitus. *Children's Health Care*, 35(2), 141–154. doi:10.1207/s15326888chc3502_3

Chaney J. M., Gamwell K. L., Baraldi A. N., Ramsey R. R., Cushing C. C., Mullins A. J., ..., Mullins L. L. (2016). Parent perceptions of illness uncertainty and child depressive symptoms in juvenile rheumatic diseases: Examining caregiver demand and parent distress as mediators. *Journal of Pediatric Psychology*, 41(9), 941–951. doi:10.1093/jpepsy/jsw004

Czuchta D. M., McCay E. (2001). Help-seeking for parents of individuals experiencing a first episode of schizophrenia. *Archives of Psychiatric Nursing*, 15(4), 159–170. doi:10.1053/apnu.2001.25415

Dodgson J. E., Garwick A., Blozis S. A., Patterson J. M., Bennett F. C., Blum R. W. (2000). Uncertainty in childhood chronic conditions and family distress in families of young children. *Journal of Family Nursing*, 6(63), 252–266.

Granrud M. D., Ludvigsen E., Andershed B. (2014). Parents' experiences of their premature infants' transportation from a university hospital NICU to the NICU at two local hospitals. *Journal of Pediatric Nursing*, 29(4), e11–e18. doi:10.1016/j.pedn.2014.01.014

Håkstad R. B., Obstfelder A., Øberg G. K. (2016). Parents' perceptions of primary health care physiotherapy with preterm infants: Normalization, clarity, and trust. *Qualitative Health Research*, 26(10), 1341–1350. doi:10.1177/1049732315608137

Han P. K., Klein W. M., Arora N. K. (2011). Varieties of uncertainty in health care: A conceptual taxonomy. *Medical Decision Making*, 31(6), 828–838. doi:10.1177/0272989X11393976

Hayeems R. Z., Miller F. A., Barg C. J., Bombard Y., Carroll J. C., Tam K., ..., Guttmann A. (2017). Psychosocial response to uncertain newborn screening results for cystic fibrosis. *Journal of Pediatrics*, 184, 165–171.e1. doi:10.1016/j.jpeds.2017.01.049

He S., You L. M., Zheng J., Bi Y. L. (2016). Uncertainty and personal growth through positive coping strategies among Chinese parents of children with acute leukemia. *Cancer Nursing*, 39(3), 205–212. doi:10.1097/NCC.0000000000000279

Hinton D., Kirk S. (2017). Living with uncertainty and hope: A qualitative study exploring parents' experiences of living with childhood multiple sclerosis. *Chronic Illness*, 13(2), 88–99. doi:10.1177/1742395316664959

Holm K. E., Co D., Patterson J. M., Rueter M. A., Wamboldt F; National Jewish Medical and Research Center. (2008). The impact of uncertainty associated with a child's chronic health condition on parents' health. *Families, Systems & Health*, 26(3), 282–295. doi:10.1037/a0012912

Kerr A. M., Haas S. M. (2014). Parental uncertainty in illness: Managing uncertainty surrounding an “orphan” illness. *Journal of Pediatric Nursing*, 29(5), 393–400. doi:10.1016/j.pedn.2014.01.008

Kerr A. M., Harrington N. G., Scott A. M. (2019). Communication and the appraisal of uncertainty: Exploring parents' communication with credible authorities in the context of chronic childhood illness. *Health Communication*, 34(2), 201–211. doi:10.1080/10410236.2017.1399508

Lasiuk G. C., Comeau T., Newburn-Cook C. (2013). Unexpected: An interpretive description of parental traumas' associated with preterm birth. *BMC Pregnancy and Childbirth*, 13(Suppl. 1), S13. doi:10.1186/1471-2393-13-S1-S13

Lin L., Yeh C. H., Mishel M. H. (2010). Evaluation of a conceptual model based on Mishel's theories of uncertainty in illness in a sample of Taiwanese parents of children with cancer: A cross-sectional questionnaire survey. *International Journal of Nursing Studies*, 47(12), 1510–1524. doi:10.1016/j.ijnurstu.2010.05.009

Madeo A. C., O'Brien K. E., Bernhardt B. A., Biesecker B. B. (2012). Factors associated with perceived uncertainty among parents of children with undiagnosed medical conditions. *American Journal of Medical Genetics, Part A*, 158A(8), 1877–1844. doi:10.1002/ajmg.a.35425

Mccormick K. M. (2002). A concept analysis of uncertainty in illness. *Journal of Nursing Scholarship*, 34(2), 127–131. doi:10.1111/j.1547-5069.2002.00127.x

Nelson P. A., Kirk S. A., Caress A. L., Glenny A. M. (2012). Parents' emotional and social experiences of caring for a child through cleft treatment. *Qualitative Health Research*, 22(3), 346–359. doi:10.1177/1049732311421178

Nightingale F. (1992). *Notes on nursing: What it is and what it is not*. Philadelphia, PA: J.B. Lippincott.

Obas K. A., Leal J. M., Zegray M., Rennick J. E. (2016). Parental perceptions of transition from intensive care following a child's cardiac surgery. *Nursing in Critical Care*, 21(3), e1–e9. doi:10.1111/nicc.12202

Obeidat H. M., Bond E. A., Callister L. C. (2009). The parental experience of having an infant in the newborn intensive care unit. *The Journal of Perinatal Education*, 18(3), 23–29. doi:10.1624/105812409X461199

Page M. C., Fedele D. A., Pai A. L., Anderson J., Wolfe-Christensen C., Ryan J. L., Mullins L. L. (2012). The relationship of maternal and child illness uncertainty to child depressive symptomotology: A mediational model. *Journal of Pediatric Psychology*, 37(1), 97–105. doi:10.1093/jpepsy/jsr055

Penrod J. (2001). Refinement of the concept of uncertainty. *Journal of Advanced Nursing*, 34(2), 238–245. doi:10.1046/j.1365-2648.2001.01750.x

Rodgers B., Knafl K. (2000). *Concept development in nursing: Foundations, techniques, and applications* (2nd ed.). Philadelphia, PA: W.B. Saunders.

Rodgers B. L. (1989). Concepts, analysis and the development of nursing knowledge: The evolutionary cycle. *Journal of Advanced Nursing*, 14(4), 330–335.

Santacroce S. J. (2001). Measuring parental uncertainty during the diagnosis phase of serious illness in a child. *Journal of Pediatric Nursing*, 16(1), 3–12. doi:10.1053/jpdn.2001.20547

Santacroce S. (2002). Uncertainty, anxiety, and symptoms of posttraumatic stress in parents of children recently diagnosed with cancer. *Journal of Pediatric Oncology Nursing*, 19(3), 104–111. doi:10.1177/104345420201900305

Santacroce S. J. (2003). Parental uncertainty and posttraumatic stress in serious childhood illness. *Journal of Nursing Scholarship*, 35(1), 45–51. doi:10.1111/j.1547-5069.2003.00045.x

Shannon M., Lee K. A. (2008). HIV-infected mothers' perceptions of uncertainty, stress, depression and social support during HIV viral testing of their infants. *Archives of Women's Mental Health*, 11(4), 259–267. doi:10.1007/s00737-008-0023-8

Stewart J. L., Mishel M. H. (2000). Uncertainty in childhood illness: A synthesis of the parent and child literature. *Scholarly Inquiry for Nursing Practice*, 14(4), 299–319.

Stratton K. M. (2004). Parents expereinces of their child's care during hospitalization. *Journal of Cultural Diversity*, 11(1), 4–11.

Tackett A. P., Cushing C. C., Suorsa K. I., Mullins A. J., Gamwell K. L., Mayes S., ..., Mullins L. L. (2016). Illness uncertainty, global psychological distress, and posttraumatic stress in pediatric cancer: A preliminary examination using a path analysis approach. *Journal of Pediatric Psychology*, 41(3), 309–318. doi:10.1093/jpepsy/jsv093

Tluczek A., Mckechnie A. C., Lynam P. A. (2010). Modified uncertainty theory and parents' perspectives about equivocal diagnostic results for cystic fibrosis. *Qualitative Health Research*, 20(2), 209–223. doi:10.1177/1049732309356285

Tong A., Lowe A., Sainsbury P., Craig J. C. (2008). Experiences of parents who have children with chronic kidney disease: A systematic review of qualitative studies. *Pediatrics*, 121(2), 349–360. doi:10.1542/peds.2006-3470

Truitt M., Biesecker B., Capone G., Bailey T., Erby L. (2012). The role of hope in adaptation to uncertainty: The experience of caregivers of children with Down syndrome. *Patient Education and Counseling*, 87(2), 233–238. doi:10.1016/j.pec.2011.08.015

Watson G. (2011). Parental liminality: A way of understanding the early experiences of parents who have a very preterm infant. *Journal of Clinical Nursing*, 20(9-10), 1462–1471. doi:10.1111/j.1365-2702.2010.03311.x

White Z., Gilstrap C., Hull J. (2017). “Me against the world”: Parental uncertainty management at home following neonatal intensive care unit discharge. *Jouranl of Family Communication*, 17(2), 105–116. doi:10.1080/15267431.2016.1233105

Whitmarsh I., Davis A. M., Skinner D., Bailey D. B. Jr.(2007). A place for genetic uncertainty: Parents valuing an unknown in the meaning of disease. *Social Science and Medicine*, 65(6), 1082–1093. doi:10.1016/j.socscimed.2007.04.034

Zierhut H. A., Bartels D. M. (2012). Waiting for the next shoe to drop: The experience of parents of children with fanconi anemia. *Journal of Genetic Counseling*, 21(1), 45–58. doi:10.1007/s10897-011-9394-5