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Parental Uncertainty in Illness: Managing Uncertainty Surrounding an "Orphan" Illness[1]

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Parents of children with complex chronic illnesses experience substantial uncertainty that is heightened when the condition is an "orphan" illness not belonging to one medical specialty. The current study explores uncertainty experienced by parents of children with "orphan" illnesses requiring multidisciplinary care. Method: Participant-observations over 13 months (n = 200) were combined with questionnaire data (n = 55) to assess parental uncertainty at a multidisciplinary pediatric clinic. Results: Five unique types of uncertainty emerged from a grounded analysis (Glaser & Strauss, 1967), revealing 11 interrelated uncertainties these parents experience. Findings can help providers understand parents' uncertainty and assist in family-centered decision-making.

WHEN CHILDREN ARE diagnosed with chronic illnesses, parents make a radical shift from a life of taken-for-granted expectations to a life of heightened uncertainty (Cohen, 1993), lack of control, and less optimism (Madeo, O'Brien, Bernhardt, & Biesecker, 2012). One source of uncertainty is a lack of adequate information about the illness (Clarke-Steffen, 1993). For example, parents of children born with vascular anomalies (i.e., birthmarks) experience uncertainty because one consistent terminology does not exist to diagnose the condition (Rieu & Festen, 1996). Consequently, nearly 60% of vascular anomalies are misdiagnosed (Patel & Curry, 2010). Although some vascular anomalies are easily treated, some complex anomalies can be life-threatening if left untreated and can cause blood clots, limb length discrepancies, seizures, and intellectual deficiencies (Patel & Curry, 2010). Many birthmarks also affect other parts of the body, including major organs. Therefore, the complex nature of vascular anomalies requires coordinated care by physicians from multiple disciplines (Richter & Friedman, 2012). The need for multiple specialists classifies birthmarks as "orphan" illnesses not belonging to one medical specialty. The multifaceted nature of vascular anomalies provides an ideal context for studying parental uncertainty. The purpose of this study is to explore uncertainty experienced by parents who face unclear diagnosis and treatment options.

Uncertainty exists when situations are unpredictable, often due to inconsistent or unavailable information (Brashers, 2001). Therefore, *illness* uncertainty stems from the struggle to categorize symptoms and information associated with one's health, inhibiting the ability to predict outcomes (Mishel, 1988). Mishel's (1988) theory of uncertainty in illness outlines four types of illness uncertainty: (a) ambiguity concerning the state of the illness, (b) complexity regarding treatment and systems of care, (c) lack of information about the diagnosis and seriousness of the illness, and (d) unpredictability of the course of the disease and prognosis. Additionally, uncertainty can simultaneously be medical, social, and personal–forcing individuals with chronic illnesses to integrate uncertainty into daily life (Brashers et al., 2003; Mishel, 1999).

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Contrary to previous assumptions that uncertainty is a negative experience reduced by seeking information, recent research suggests more information can actually intensify uncertainty by increasing alternatives or suggesting unwanted outcomes (Brashers et al., 2000; Shannon & Weaver, 1949). Ultimately, uncertainty can only be reduced if information is adequate for decision-making purposes (Clatterbuck, 1978; Sheer & Cline, 1995). However, information that helps answer one question often introduces new questions and uncertainties (Babrow & Dutta-Bergman, 2003). This "chaining of uncertainties" suggests uncertainty cannot be isolated, but exists in relation to other uncertainties (Babrow, 2001). Thus, information seeking might not always be the most helpful strategy for managing uncertainty (Brashers, 2001). Instead, uncertainty management theory (UMT) proposes that individuals communicate in a variety of ways to *manage* uncertainty depending on their appraisal of uncertainty (Brashers, 2001; Brashers et al., 2000).

According to uncertainty management theory (Brashers et al., 2000; Brashers, 2001), uncertainty manifests differently for different people and in different situations. Consequently, individuals may seek *or* avoid information to eradicate, cultivate, or maintain feelings of uncertainty depending on their appraisal. When uncertainty is appraised as a danger, individuals generally seek relevant information to clarify alternatives (Hogan & Brashers, 2009) or relieve discomfort (Bradac, 2001). If uncertainty is perceived as a way to maintain hope, seeking information can help amplify uncertainty by increasing alternatives or challenging existing beliefs (Brashers et al., 2000; Hogan & Brashers, 2009). Individuals may also avoid information to maintain uncertainty and avoid unwanted outcomes (Barbour, Rintamaki, Ramsey, & Brashers, 2012). Contrary to previous uncertainty theories, UMT posits that more information can often increase uncertainty, so managing information becomes important. Consequently, individuals with chronic illnesses must adapt to chronic uncertainty through continued reappraisals over the trajectory of their illness (Brashers et al., 2000), which results in adequately seeking and avoiding information as necessary. Adapting to chronic uncertainty is vital for parents of children with chronic illnesses.

Parents' illness uncertainty stems from parents' desire to envision their child's future (Santacroce, 2001). Uncertainty is typically intensified during the diagnosis phase of the illness when parents experience uncertainty about the severity of the illness and the unpredictability of the future (Clarke-Steffen, 1993). Uncertainty also manifests in fear of the pain the child might endure and the possibility of death (Binger et al., 1969). Not surprisingly, parents with higher levels of uncertainty often report a lack of personal control, less optimism, and higher perceptions of disease severity when their child's medical condition is unknown (Madeo et al., 2012). Therefore, when parents do assign meaning to the illness, they often do so negatively because of the perceived threat to the health of the child (Hoff et al., 2005). Therefore, the uncertainty associated with chronic illness can cause high levels of stress (Dodgson et al., 2000; Santacroce, 2003).

Parents of children with chronic 'orphan' illnesses, such as vascular anomalies, experience uncertainty because of the complexity of care. Vascular anomalies are a challenge for physicians because each occurrence is unique (Rieu & Festen, 1996). Many physicians are willing to treat uncomplicated birthmarks, such as port-wine stains, but less willing to treat, or even diagnose, complex anomalies (Mathes, Haggstrom, Dowd, Hoffman, & Frieden, 2004). These multifaceted vascular anomalies require care from physicians from numerous disciplines to diagnose and to manage (O'Regan et al., 2007). Consequently, patients risk being misdiagnosed or mismanaged if the right physicians are not consulted (Mathes et al., 2004). The review of previous literature suggests parents experience unique uncertainty while caring for a child in the context of multidisciplinary care and in the face of inadequate information. The goal of this study is to examine and extend existing constructions of uncertainty by exploring how parents of children with vascular anomalies experience and manage uncertainty.

Methods

Data for this study were collected through triangulating participant-observations, discussions with parents, and an open-ended questionnaire at a multidisciplinary vascular anomalies clinic within a large midwestern children's hospital. The study was approved by the authors' institutional review board, and all participants provided informed consent prior to study involvement. Parents were asked to participate in the study when they arrived for their child's appointment and provided informed consent at that time. One author also visited the clinic weekly over 13 months to observe over 200 physician–parent–child interactions in the exam room as well as interactions among the multi-disciplinary team members. Youth assent was attained if the child (patient) was between the ages of 11 and 17. Although the children (patients) did not complete the survey instrument, the youth assent was required for the observation of the clinic visit during which the child would be present.

Instrument

Data were collected through triangulating participant-observation, discussions with parents, and an open-ended questionnaire developed after several months of participant-observations. Parents completed the questionnaire in the waiting or exam room before seeing