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Children With Chronic Conditions: Perspectives on Condition Management

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This qualitative study described children's (8–13 years old) perspectives of their chronic health conditions (e.g., asthma, diabetes, cystic fibrosis): how they perceived their condition, its management, and its implications for their future. The study used the family management style framework (FMSF) to examine child perspectives on the joint venture of condition management between the child and family. Children within this age group viewed condition management in ways similar to their parents and have developed their own routines around condition management. Future studies of this phenomenon comparing child and parent perspectives would further our understanding of the influence of family management.

CHILDREN WITH CHRONIC health conditions (CHCs) learn how to manage their conditions through everyday life experiences with their families, peers, health providers, and others in their communities. While most studies using children's perspectives describe disease specific management issues and tend to be more skill related, non-categorical or non-disease-specific issues are largely overlooked (Wollenhaupt, Rodgers, & Sawin, 2012). Non-categorical studies, because they may be applied to a multitude of conditions, may be of special benefit to future clinical practice, health care policy, and research (Rolland, 1994). The purpose of this qualitative descriptive study was to systematically describe the understandings of condition management from the perspectives of school-aged children (8–13 years) with a variety of CHCs.

School-aged children are transitioning from concrete ways of thinking to cognitive thought processes that are more complex and intellectual (Vygotsky [1967], 2004). Children's understanding also varies according to everyday experiences. The lives of children with CHC are filled with daily reminders and potential learning experiences related to their condition (Crisp, Ungerer, & Goodnow, 1996; McMenamy & Perrin, 2008). Although the family remains the main source of information and guidance for the school-aged child, sustained encounters outside the home and family environment provide opportunities for expanded experiences (Coll & Szalacha, 2004). Thus, school-aged children with CHCs begin to learn how to navigate life and their conditions outside the home. Their families are then challenged to expand condition management from the home to include the school and the community as their children engage in these settings and rely more on adults outside the family structure (Emiliani, Bertocchi, Poti, & Palareti, 2011).

The family management style framework (FMSF) (Figure 1) was developed using symbolic interactionism (Blumer, 1969) to describe the process of family management, identifying how families define the condition, manage it, and perceive the consequences of the condition (Knafl, Deatrick, & Havill, 2012). The FMSF has been used to explore family management of a variety of conditions in a non-categorical or non-disease-specific manner and to identify the domains or categories that are common across disease entities, with findings applicable to a wide range of health conditions (Knafl et al., 2012). The major components within the framework, including definition of the situation, management behaviors, and perceived consequences,

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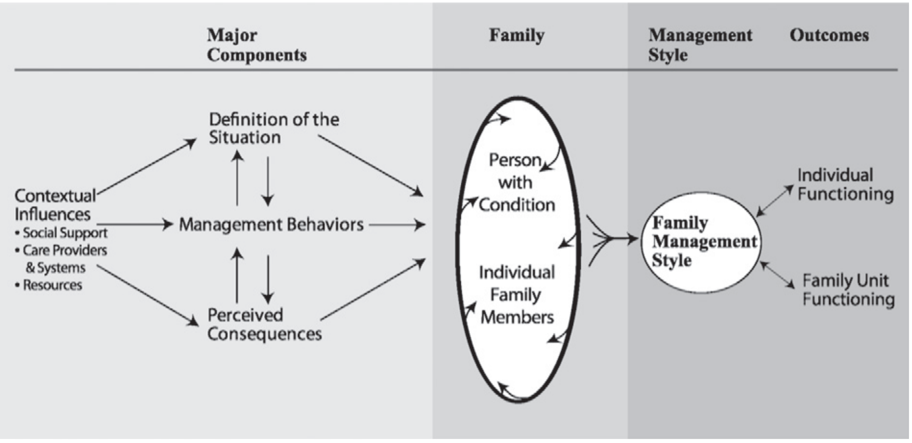

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Figure 1 Current model of the family management style framework.

provide us with the parents' perspectives on non-disease specific condition management, that is, how they see the child and the condition, the amount of effort it takes to manage the condition and the disruption the condition causes the family, and the way the parents are thinking about the child's future (Knafl et al., 2012). The FMSF was developed predominantly from information gathered from the parents of children with CHCs, but as can be seen from the framework, differentiates family members and the person with the condition. This study adds the perspectives of school-aged children with CHCs within the context of family management and describes how these children understand their condition and incorporate it into their daily lives.

Design and Methods

This qualitative, descriptive study identified the perspectives of school-aged children with CHCs using directed content analysis. Directed content analyses are based on an a priori framework that guide the creation of interview guide and analytic codes (Hsieh & Shannon, 2005). The FMSF dimensions (defining, managing, and perceived consequences of the condition) directed the development of the interview guide as well as the analysis of the interviews. Data were collected through interviews with children who had been diagnosed with a CHC for at least six months and were between 8 and 13 years of age. A six-month lag from diagnosis ensured that the child and family had time to understand the reality of the diagnosis and develop an approach to condition management.

Setting and Sample

Thirty-two children with a variety of CHCs were recruited from three ambulatory clinics (endocrine, hematology, and pulmonary) in a large pediatric hospital located in the northeastern U.S. Both the hospital and the university with which it is affiliated granted IRB approval for the study prior to any recruitment activities. A purposeful, maximum variation sampling strategy was used to recruit a sample with a wide variety of condition experiences (Patton, 2002). A three-pronged approach to recruitment was used: 1) clinic recruitment via posters in the waiting room and referral from the health care provider; 2) mailings to families meeting the inclusion criteria; and 3) word of mouth. Interested parents contacted the study via phone or return mail inquiry, were contacted by phone, provided verbal consent, and then provided screening information regarding inclusion criteria and condition characteristics. If the screening criteria were met an appointment for the home interview was made. At the beginning of the interview, the first author who was principal investigator reviewed the study information with the parent and the child, answered any questions, and obtained informed consent/assent. It was made clear throughout the process that participation was voluntary.

Data Collection

The first author conducted the interviews between June 2012 and January 2013. Most of the interviews (n = 30) were held at participants' homes, although two families preferred to meet at an alternative setting, one at the local YMCA and the other at the university. While the qualitative interview data were collected from the child with a CHC, the parent completed demographic information and surveys about the child and the family (Table 1). For reporting purposes a primary/recruitment CHC was identified for each child; however, over half of the children in the sample had more than one CHC.