ARTICLE

Kawasaki Disease With Coronary Artery Aneurysms: Psychosocial Impact on Parents and Children

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ABSTRACT

Introduction: For those living with Kawasaki disease and coronary artery aneurysms, little is known about the psychosocial burden faced by parents and their children.

Methods: Exploratory, descriptive, mixed-methods design examining survey and interview data about health-related uncertainty, intrusiveness, and self-efficacy.

Results: Parents' uncertainty was associated with missed diagnosis, higher income, and maternal education. Higher uncertainty scores among children were associated with absence of chest pain and lower number of echocardiograms. High intrusiveness scores among parents were associated with previous cardiac catheterization, use of anticoagulants, lower parent education and income, and missed diagnosis. High intrusiveness scores among children were associated with high paternal education. Children's total self-efficacy scores increased with chest pain and larger aneurysm size. Qualitative analysis showed two central themes: *Psychosocial Struggle* and *Cautious Optimism*.

Discussion: Negative illness impact is associated with a more intense medical experience and psychosocial limitations. Timely assessment and support are warranted to meet parents' and children's needs. J Pediatr Health Care. (2016) ■, ■-■.

KEY WORDS

anxiety, children, coronary artery aneurysms, Kawasaki disease, psychosocial functioning, uncertainty

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INTRODUCTION

A leading cause of pediatric acquired heart disease (Singh, Vignesh, & Burgner, 2015), Kawasaki disease (KD) is an acute, febrile, systemic vasculitis that primarily affects young children (Devins et al., 1983; Lin et al., 2010) with incidence varying by age, race, and ethnicity (Uehara & Belay, 2012); worldwide incidence is roughly 17.5 to 20.8 per 100,000 for children 5 years of age or younger (Singh, et al., 2015). Coronary artery aneurysms (CAAs) can develop in 25% of untreated patients, with the prevalence reduced to approximately 4% if treated with intravenous immunoglobulin within 10 days of illness onset (McCrindle, 2009; Newburger et al., 2004). The diagnosis of KD is challenging and is dependent on clinical presentation and laboratory test results (Bandura, Pastorelli, Barbaranelli, & Caprara, 1999; Cimaz & Sundel, 2009). Caring for children with KD and CAA is complex and requires long-term follow up and management (Bandura et al., 1999; Dimitriades, Brown, & Gedalia, 2014; Manlhiot, Niedra, & McCrindle, 2013). These children are at a higher risk for future cardiovascular complications and/or myocardial infarction. Both the children and their parents are faced with ongoing uncertainties about treatment, complications, and prognosis (Falcini, Capannini, & Rigante, 2011). The fear of an unknown future may negatively affect family functioning and child development (Baker et al., 2003; Chahal et al., 2010).

Uncertainty is a state involving a lack of information, ambiguity, unpredictability, or the inability to control or predict outcomes accurately (Cypress, 2016; Merriam-Webster, 2011; Mishel, 1988). In the KD population, little has been reported about family perceptions and relationships that may result from illness uncertainty, intrusiveness, prognosis, and treatment inconsistency. Our previous investigation explored anxiety among parents of children with KD (Chahal et al., 2010). The purpose of this research was to expand our understanding of the contributors to and the specific experiences of uncertainty, intrusiveness, and coping among families (parents and older children) experiencing the complexities of KD and CAA.

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METHODS

Design

Over the course of 1 year (October 2013 through October 2014), this exploratory, descriptive, mixed-methods study included pediatric KD patients/families routinely followed for CAA in the cardiology clinic at a large urban children's hospital in southern Ontario. The study received approval from the Research Ethics Board at the Hospital for Sick Children, Toronto, Canada.

Recruitment and Sample

A total of 39 parents of eligible patients (KD with CAA) were identified from the clinic appointment schedule during the planned study period. We excluded families if the child was newly diagnosed, there was a significant developmental delay, and/or they did not speak English. For those eligible, a telephone call was placed to the parent to describe the study and invite participation. Eight declined participation (six refused, and two had a scheduling conflict). The final convenience sample (Figure 1) included children ages 10 to 17 years (n = 16) and parents (n = 31) who were willing to complete a set of questionnaires and participate in an interview during their routine clinic appointments. A parent of an eligible family reported that they believed their child (>10 years) was not well suited for participation in this study because of a cognitive developmental delay. Although the child was excluded from participation, the parent was enrolled, and the child's clinical data were used in our analysis.

Parents were mailed study information and a copy of the consent forms 1 month before the child's upcoming clinic appointment. Families were telephoned 2 weeks before the appointment by the cardiology clinic's nurse practitioner, who described the study once again and obtained verbal consent. Signed consent and assent forms were obtained by the research assistant on the day of the clinic appointment.

Study Measures

Routine assessment, medical records, and personal data

All children underwent their standard, routine testing and anthropometric assessments. The nurse practitioner completed each child's physical examination and reviewed his/her medical records for a complete medical history (Table 1). Parents completed a background information form for additional demographic details (Table 2).

Psychometric measures

While awaiting their clinical assessments, child and parent participants were asked to complete a questionnaire package. Three questionnaires with acceptable psychometric properties were adapted with language specific to the KD population (with permission from the original authors) and were used to measure levels of uncertainty, intrusiveness, and self-efficacy. To measure the level of illness-related uncertainty, the Uncertainty Scale for Kids (Stewart,