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Low-Income Children, Adolescents, and Caregivers Facing Respiratory Problems: Support Needs and Preferences

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Purpose: Burdens of poverty are often compounded by respiratory problems. This study aimed to identify the support needs and intervention preferences for low-income families facing this challenge.
Design and Methods: Interviews were conducted in two Canadian provinces with low-income children/adolescents (n = 32) diagnosed with respiratory health problems and their parents or family caregiver (n = 37).
Results: These vulnerable children and parents described non-supportive interactions with some health service providers and inadequate information. They reported isolation and support deficits, exacerbated by limited resources and health restrictions. Children/adolescents felt isolated and excluded and wanted to connect with peers. Group or dyadic level support, delivered by peers and health professionals, was desired. The importance of logistics to enhance accessibility and appeal of group or dyadic support interventions was clearly identified.
Conclusions: The findings of this study reveal that low-income children and their families encounter challenges to accessing support and to utilizing support resources.
Practice Implications: Partnerships with low-income children/adolescents and family caregivers in provision of education and social support can combat isolation and ignorance. Reducing inequities for this high risk population could be achieved by providing support from experienced peers, in combination with health professional guidance, and knowledge about pulmonary health.

Low-income families face major health challenges and barriers to health services and social supports (Reutter et al., 2009; Williamson et al., 2006). Within these families, approximately 1.2 million children in Canada live in poverty; 49% of recent immigrant/refugee children and over half of Aboriginal children are poor (Bianchi, Clavenna, & Bonati, 2010; Chang, Beach, & Senthilselvan, 2012; Gao, Rowe, Majaesic, O'Hara, & Senthilselvan, 2008). Exposure to environmental problems (e.g., pollution, smoking) and inadequate access to health services place children in low-income families at high risk of respiratory problems (Chang et al., 2012).

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Children with respiratory disease from low-income families also experience lower quality of life compared to children from more affluent families (Blais, Beauchesne, & Levesque, 2006).

Some respiratory health conditions, such as asthma, are particularly prevalent in low-income children (Chen, Tang, Krewski, & Dales, 2002; Kozyrskyj, Kendall, Jacoby, Sly, & Zubrick, 2010). Canadian investigations reveal that low-income children with asthma have a higher risk of hospitalization, lower use of other health services (To, Dell, Tassoudji, & Wang, 2009; Trachtenberg, Dik, Chateau, & Katz, 2014), and higher rates of non-adherence to medication regimen (Ungar et al., 2011) than higher income children. Low-income families use more urgent care and less preventive care for their children's asthma than more affluent families (Blais et al., 2006; Gong et al., 2014; Seung & Mittman, 2005).

Barriers to accessing health services for low-income families include; Canada's wide-spread population, diversity of language and culture, health care coverage which does not include medication costs (Boulet & Chapman, 1994), and lack of coordination among health professionals. Access to specialty asthma services can be problematic because of restricted hours of operation, transportation and parking expenses, and required referral by a primary care physician (Cicutto et al., 2005).

Studies reveal social isolation, loneliness, and significant gaps in social support for children and adolescents affected by asthma (Knight, 2005; McQuaid, Kopel, Klein, & Fritz, 2003; Morawska, Gregory, & Burgess, 2012). Poverty is also linked with social support deficiencies and social isolation (Couriel, 2003; McQuaid et al., 2003). The World Health Organization (WHO Commission on Social Determinants of Health, 2008) reinforces the salient role of social support and social networks as a key determinant of health, a health promotion mechanism, and a protective factor in resilience. Interactions and relationships with members of social networks can be supportive or non-supportive and can exert beneficial or detrimental effects on physical, psychological, and spiritual health (Stewart, 2009). Children and their families need access to varied support resources—emotional, informational, affirmational, and practical support—from family, friends, co-workers, and service providers (Stewart et al., 2008).

People living in poverty have access to fewer social support resources than higher-income people and their limited resources can be depleted by providing for basic needs (Stewart et al., 2008). However, support interventions aimed at children/adolescents with asthma and their families have not focused on the support needs of low-income families (Basch, 2011; Cope, Ungar, & Glazier, 2008). To design interventions that support children and family caregivers dealing with complex respiratory health challenges (Knafl & Gilliss, 2002), collective stressors (e.g., poverty and illness) requiring support, support resources, support needs, and support intervention preferences should be assessed. Prior to launching the study reported here, our review revealed that no studies investigated challenges accessing supports, support resources, support needs, and support intervention preferences from the perspectives of both low-income children/adolescents affected by respiratory conditions and their family caregivers.

Purpose

The aim of this study was to assess challenges accessing support, support resources, support needs, and support intervention preferences of children/adolescents and their family caregivers affected by both poverty and respiratory health problems, such as cystic fibrosis and asthma.

Four research questions guided this study: (1) What are the perceptions of low-income children/adolescents and family caregivers, affected by respiratory health problems, regarding challenges accessing support? (2) What support resources are important for low-income children/adolescents and family caregivers dealing with respiratory health challenges? (3)What support needs are identified by low-income children/adolescents facing respiratory health challenges and their family caregivers? (4) What are the support intervention preferences of low-income children/adolescents affected by respiratory health problems and their family caregivers?

Design and Methods

Community-based participatory research strategies (Bergold & Thomas, 2012; Harrison & Graham, 2012; Vaughn, Wagner, & Jacquez, 2013) guided the research. Participatory research seeks to improve participants' quality of life through their involvement in a process that utilizes their knowledge in finding solutions for their problems. Four elements of participatory research were integral to this study (Reutter et al., 2005). First, community research assistants, who had personal experience with poverty and respiratory health problems, co-facilitated group interviews of family caregivers and of children/adolescents. Second, community advisory committees composed of representatives from low-income, advocacy organizations for people living in poverty, community agencies serving low-income families, and agencies serving people with chronic respiratory health conditions were created to ensure relevance of the research for enhancing services for low-income people. These advisory committees helped guide the research process, selection and training of project staff, development of interview guides, recruitment, and knowledge translation strategies. Third, low-income children and family caregivers identified their support needs and specified the types of support interventions they wanted to address their unique needs. Fourth, partnerships were developed with community agencies serving low-income people to implement the research, recruit participants, enhance accessibility for participants, and disseminate research findings (Reutter et al., 2005).

The interpretive description type of qualitative methods used in this study focuses on questions of inquiry relevant to practice to generate "better understandings of complex experiential clinical phenomena within nursing and other professional disciplines" (Thorne, 2008, p. 26-27). Qualitative methods were employed to explore perceptions, beliefs,