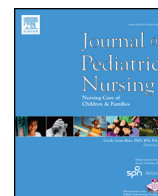




Contents lists available at ScienceDirect

Journal of Pediatric Nursing



Parents' Perspectives on Their Child's Social Experience in the Context of Childhood Chronic Illness: A Qualitative Study

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ARTICLE INFO

Article history:

Received 6 April 2018
Revised 20 June 2018
Accepted 23 June 2018
Available online xxxx

Keywords:

Chronic illness
Paediatric
Social
Psychosocial
School

ABSTRACT

Purpose: Many children suffer from a serious chronic illness. These children have greater risks of developing psychosocial difficulties, associated with school absenteeism and missed social opportunities. Through parents' perspectives, this study aimed to gain a holistic understanding of children's social experience in the context of chronic illness.

Design and Methods: We conducted semi-structured interviews with parents of a child with a serious chronic illness exploring their child's school experience. Two researchers coded social experiences using an iterative process, involving regular team discussions. Theoretical thematic analysis and content analysis were both performed, using the social ecological model as a theoretical framework.

Results: Forty-nine parents participated (43 mothers, 6 fathers; child mean age 11.51 years; 21 female children, 28 male children; 6 different chronic illness groups). According to parents, the main facilitators to the social experience of their children involved parents themselves, the school, social networks and peers, as they were all able to provide social support and opportunities for social development. However, peers were also a source of bullying and peer pressure, and sometimes lacked understanding and empathy.

Conclusions: As shown by the social ecological model, social functioning between chronically-ill children and their peers can be influenced by many factors. More specifically, parents have expressed their ability for promoting positive experiences between their children and their peers.

Practice Implications

Considering the complexity of social functioning, future research and interventions should provide holistic support for children with chronic illnesses.

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Introduction

Chronic health conditions are defined as “an ongoing impairment characterised by a physical or mental condition, functional limitation, and service use or need beyond routine care” (Milnes et al., 2011). These conditions affect a significant number of young Australians. In 2011, around 17% of young Australians were suffering from a chronic condition with activity limitation (Ferguson & Walker, 2014; Milnes et al., 2011), and similar numbers were found in the American population (Newacheck & Taylor, 1992).

New and evolving treatments, coupled with refined patient management, have led to increased life expectancy and functional abilities

associated with severe chronic conditions (Falvo, 2013; Madan-Swain, Katz, & LaGory, 2004). This necessitates an increased focus on maintaining quality of life, with many children suffering from long-term complications associated with their illness and treatment (Armstrong & Reaman, 2005). For example, survivors of childhood cancer, who are in remission, have high risk of developing subsequent neoplasms, cardiac and pulmonary diseases, among many other complications (Armstrong et al., 2016).

Chronic health conditions can severely disrupt a child's development and wellbeing (Milnes et al., 2011) and place children at an increased risk of developing psychosocial difficulties (Meijer, Sinnema, Bijstra, Mellenbergh, & Wolters, 2000). Social functioning is a key component of a child's quality of life. It encompasses both social competence, which is the potential social skills and abilities of a child; and social performance, the actual and measurable social behaviour of that child (Pinquart & Teubert, 2012; Schunk & Pajares, 2005).

Children with a chronic illness have school absenteeism rates over five times higher than their healthy peers (McDougall et al., 2004;

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Prevatt, Heffer, & Lowe, 2000). An average of 16 days is missed per year across all illnesses, and over 40 days on average for children with leukaemia during the first stages of treatment (McDougall et al., 2004; Prevatt et al., 2000). The combination of school absenteeism and missed social opportunities due to the condition itself or associated treatments, can lead to delays in social development and adjustment, social isolation, and difficulty with the achievement of developmental milestones (DeWalt et al., 2013; Stam, Hartman, Deurloo, Groothoff, & Grootenhuis, 2006; Suris, Michaud, & Viner, 2004; Taylor, Gibson, & Franck, 2008; Yeo & Sawyer, 2005). Developing and maintaining friendships is one of the main challenges affecting children with chronic illnesses, the timing of which, during a critical period of social development, may also lead to long-term impacts (Klimstra, Beyers, & Besevegis, 2014; McLoone, Wakefield, & Cohn, 2013; Taylor et al., 2008; Zebrack, 2011).

Much of the past research has predominantly focused on children's experiences of school-related social difficulties. However, an understanding of the factors that minimise these difficulties is required to create effective support strategies for children with chronic illness (Ferguson et al., 2005; Ferguson & Walker, 2014). While many children with chronic illnesses demonstrate great resilience, maturity and social functioning (Bitsko et al., 2016; Cassano, Nagel, & O'Mara, 2008; Ferguson & Walker, 2014), the protective factors contributing to resilience and healthy social functioning in the school setting are poorly understood. The Keeping Connected project by Ferguson and Walker (2014) studied children with a wide range of medical conditions, and demonstrated those who sustained connections or reconnected with school and friends successfully were more likely to use specific coping mechanisms. These included reflecting on one's personal situation, and staying in contact with friends during and after treatment. While it is important to understand barriers to social functioning and risk factors for poor social adjustment, facilitators and strategies promoting social functioning should be emphasized and analysed in a similar manner (Ferguson & Walker, 2014).

One way to conceptualise social functioning is using the model of social ecology, first developed by Bronfenbrenner (1979) and specifically applied to paediatric illnesses by Kazak (2006) (Fig. 1). A child's health and quality of life are influenced by various factors, which can be arranged into interactive systems.

This theoretical framework analyses different systems and their interactions in relation to a child's health, allowing for a comprehensive

and systematic approach to understanding barriers and facilitators of social functioning at different levels of influence. This model is formed by a core representing the individual, surrounded by three concentric systems: a microsystem, exosystem and macrosystem (Bronfenbrenner, 1979). The individual refers to the child themselves, their inner traits and characteristics including their illness. The microsystem is the closest environment in which the child is developing, with stakeholders who are in direct contact with the children, encompassing the family, parents and siblings. The exosystem is the larger environment in which the child is developing, with stakeholders who are also in direct contact with the child, including the hospital, school, peers, neighbours and other social networks. Finally, the macrosystem is the broader society, which can directly or indirectly affect the child's development, including technology, social class, law, culture and religion (Bronfenbrenner, 1979; Kazak, 2006). These systems and subsystems directly or indirectly impact on the child's development and health.

As a component of the exosystem the school is a critical setting, providing social interactions and opportunities (DeWalt et al., 2013; Stam et al., 2006; Suris et al., 2004; Taylor et al., 2008; Yeo & Sawyer, 2005). Moreover, as illustrated by the above social ecological model, parents play a central role in the life and health of a child (Bronfenbrenner, 1979; Kazak, 2006). Over time, paediatric medical care has also become more family centred (Pettoello-Mantovani, Campanozzi, Maiuri, & Giardino, 2009), better enabling parents to develop a good understanding and insight into their child's condition. This makes parents a valuable target group for interventions and information resources to support children who may be struggling because of their condition. Finally, as educational and medical systems are constantly changing and being remodelled (Shaw & McCabe, 2008), the steady and consistent role of parents as advocates for their child is invaluable. Through parents' perspectives, we therefore aimed to gain an in-depth and holistic understanding of children's social functioning experiences in the context of chronic illness. The methodology of this study is underpinned by the social ecological model, shown previously in Fig. 1, developed by Bronfenbrenner and specifically applied to paediatric illnesses by Kazak (Bronfenbrenner, 1979; Kazak, 2006). This study sought to examine the following research question: what are parents' perspectives of the facilitators and barriers to social functioning at school for their child with a chronic illness?

Methods

This study formed part of a larger project aiming to investigate satisfaction with educational experiences in families of a child with a serious chronic illness. Social experiences of a child with a serious chronic illness were analysed independently for this study, underpinned by the social ecological model. Ethics approval was granted by the Sydney Children's Hospitals Network Human Research Ethics Committee.

Participants

Participants recruited for the larger project included children with and without a serious chronic illness attending primary or high school in Australia, as well as their parents. For our study, we included participants meeting the following inclusion criteria: parents of a child (1) aged 4–19 years; (2) diagnosed with a serious chronic illness; and (3) currently attending an Australian primary or high school.

Eligible participants were recruited using the national database of the Ronald McDonald Learning Program (RMLP), a non-government organisation providing tutoring to school aged children who have missed over 40 days of school due to their condition. The study was advertised via email and postal invitations sent to parents listed on the RMLP database. We also recruited patients face-to-face at four clinics at the Sydney Children's Hospital, on social media including Facebook, and through

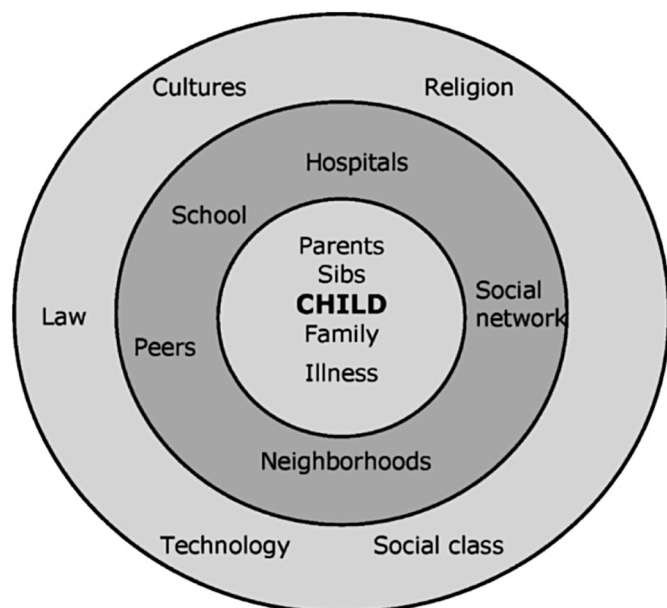


Fig. 1. Social ecological model applied to child health (Kazak, 2006).

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