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Barriers to Addressing Social Determinants of Health in Pediatric Nursing Practice: An Integrative Review

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ABSTRACT

Problem: Despite a substantial body of knowledge regarding the importance of the social determinants of health, recognizing and responding to the psychosocial circumstances of seriously and chronically ill children and their families is not well established in routine pediatric nursing care.

Eligibility Criteria: The search process focused on psychological and social determinants and care in the healthcare setting. Searches were limited to research and review publications written in the English language. The quality of evidence was graded using the National Health and Medical Research Council evidence hierarchy.

Results: Thirteen publications were identified for inclusion. Healthcare providers do recognize emotional distress experienced by patients, but feel unable to address psychosocial issues due to the lack of time, a lack of confidence in their own communication skills, and the perception that patients and their families prioritize physical care over psychosocial care. For patients and their families the main issue was that the healthcare system was focused on physical care with little opportunity to talk about psychosocial concerns.

Conclusions: The greatest barrier to addressing the social determinants of health in the pediatric context is the dominance of the 'medical model' of care. Also, many healthcare providers believe that they lack the communication skills necessary to talk about psychosocial issues.

Implications: The way forward will be to empower nurses through the sharing of knowledge of the social determinants of health, the development of skills in relationship building and therapeutic communication, and the mentorship of compassionate family-centered care.

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Contents

Introduction	0
Clinical Problem	0
Significance of the Clinical Problem	0
Search Strategy	0
Barriers to Addressing Social Determinants of Health by Families and Healthcare Providers	0
Discussion	0

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Implications for Pediatric Nursing Practice	0
Conclusion	0
References.	0

Introduction

The increased risk of emotional, behavioral, and learning problems in children who are seriously or chronically ill means that children who are affected require considerable support to maximize physical and emotional health and well-being. Managing and responding to their children's needs may be very difficult for parents. Initial experiences of shock, disbelief and distress at the time of a child's diagnosis can be replaced by hypervigilance, persistent anxiety and worry about managing the demands of family life (Cousino & Hazen, 2013). The special care needs for these children is often complex, problematic, and costly (Shattuck, 2008). Feelings of stress, overwhelm, and associated sadness can further impact the capacity of parents to cope and provide the care and reassurance their children need (Coffey, 2006).

Children who are seriously and chronically ill are more likely than children who are not, to experience perturbations in development associated with the impact of their illness on psycho-neuro-endocrine-immune pathways; the mechanisms of stress biology (McEwen & Gianaros, 2010). For example, the impact of early onset juvenile diabetes on the developing brain has long been associated with neurocognitive deficits, especially in the early years (Schwartz, Wasserman, Powell, & Axelrad, 2014). Similarly, children with cerebral palsy often experience communication challenges, learning difficulties and reduced executive functioning which can further limit participation (Morgan, Novak, & Badawi, 2013; Weierink, Vermeulen, & Boyd, 2013). Living with these limitations can be a source of frustration, anxiety and depression for children and their families especially when accompanied by additional impairments such as pain, sleep problems, vision and hearing loss, or seizures (Novak, Hines, Goldsmith, & Barclay, 2012).

Nested within developmental systems theory, the Family and Community Resource Framework proposed by Brooks-Gunn and colleagues (Brooks-Gunn, Brown, Duncan, & Anderson Moore, 1995) draws attention to the fact that some parents are better able to cope when their child is seriously or chronically ill, than others. Some families have higher levels of financial, physical, human, and social capital that significantly increase their resilience. Some parents are better able to manage their child's healthcare needs and access professional care to assist them to cope in the longer term (Kendall & Tallon, 2011). Resource levels are closely associated with socio-economic status (SES). SES is a composite measure comprised of income, education and occupation and it is useful as a general indicator of relative social and economic advantage and disadvantage.

It is evident in a great deal of population health and economic research that SES and social class are negatively associated with health outcomes (Commission on Social Determinants of Health, 2008). The relationship between SES and health resembles a gradient in which incrementally higher SES is associated with incrementally decreased risk of experiencing morbidity and death. The relationship is not confined to adults. Evidence shows that children's health and developmental outcomes, such as mental health problems, literacy and numeracy, and success at school, follow the same pattern. The social gradient in health and development holds in both developed and developing countries across the world (Commission on Social Determinants of Health, 2008).

Clinical Problem

Despite a substantial body of knowledge and understanding regarding the importance of the social determinants of health, recognizing and responding to the psychological and social circumstances of seriously

and chronically ill children and their families is not well established in routine pediatric nursing care (Gardner et al., 2014).

Significance of the Clinical Problem

When a child is seriously or chronically ill the stress and anxiety experienced by the child and his/her family can be overpowering and even bring a family to crisis point (Zebrack et al., 2014). The secondary effects of illness on parents and family relationships is well understood (Zubrick, 2000). Research findings show that having a child with cancer, for example, is associated with considerable parental stress, fatigue, and burnout (Lavelle, Wittenberg, Lamarand, & Prosser, 2014). Uncertainty, stress, and anxiety can be the source of considerable emotional tension between parents when a child is seriously ill (Da Silva, Jacob, & Nascimento, 2010). In addition to family relationships, the impact on family functioning as a result of sharing the caregiving load is also well evidenced when the rhythm of family routine is lost and usual family roles and boundaries become ambiguous (O'Brien, 2007).

The parental work schedule is often interrupted and the reduced ability to continue professional responsibilities can be a source of considerable financial strain and additional family-life stress for parents (George, Vickers, Wilkes, & Barton, 2008). In a geographically large country like Australia, some children and their families live long distances away from healthcare facilities and services. Without access to regular transport, the inability to access services easily can be a further source of stress resulting in poor attendance and limited healthcare follow up (White et al., 2011). The impact of unmet practical issues such as child care, home help, and transport have been reported where financial strain and stress are more likely to be experienced; families most affected are those from rural and remote areas (White et al., 2011). Rural and remote areas are frequently identified as areas with families facing considerable socio-economic disadvantage (ABS, 2000; AIHW, 2016).

Some parents of children who are seriously ill choose to forfeit considerable income to care for their sick children. Financial strain related to loss of work hours or family income can impact family harmony and functioning (Johnson, Li, Kendall, Strazdins, & Jacoby, 2013). The benefits of having someone to talk to for the parents of children who are seriously or chronically ill, and the value of being able to rely on family and friends for support is well evidenced (Mills et al., 2013; Tallon, Kendall, & Snider, 2015a). Having the capacity to engage with other parents and families has also been found to provide social capital which brings benefits for mental health and well-being (Coulson & Greenwood, 2012).

Given the impact of the psychosocial circumstances of seriously and chronically ill children and their families, the following question has been posed: 'Why is knowledge and understanding of the social determinants of health not addressed in routine pediatric care?' The answer to this question is explored in the following integrative review that focuses on barriers to talking about psychosocial issues reported by the families experiencing serious and chronic illness and healthcare providers.

Search Strategy

A wide range of relevant research findings were sought including both peer reviewed published research and pertinent 'grey' literature. The following databases were selected: 'CINAHL', 'Medline', 'PubMed', 'ScienceDirect' and 'Psych INFO'. Further references were identified using the reference lists from selected published articles. Throughout the search process a focus on psychological and social determinants

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