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

Mary M. Tallon [a,*], Garth E. Kendall [a,b], Lynn Priddis [c], Fiona Newall [d,e,f], Jeanine Young [g,h,i,j,k,l]

[a] *School of Nursing Midwifery and Paramedicine, Curtin University, Kent Street, Bentley, Western Australia 6102, Australia*
[b] *Telethon Kids Institute, 100 Roberts Road, Subiaco, Western Australia 6008, Australia*
[c] *School of Arts and Humanities, Edith Cowan University, 270 Joondalup Drive, Joondalup, Western Australia 6027, Australia*
[d] *Royal Children's Hospital, 50 Flemington Road, Parkville, Melbourne, Victoria 3052, Australia*
[e] *The University of Melbourne, Department of Nursing and Paediatrics, Parkville, Melbourne, Victoria 3052, Australia*
[f] *Murdoch Children's Research Institute, 50 Flemington Road, Parkville, Melbourne, Victoria 3052, Australia*
[g] *The University of the Sunshine Coast, School of Nursing, Midwifery and Paramedicine, Locked Bag 4, Maroochydore DC, Queensland 4558, Australia*
[h] *SIDS and Kids National Scientific Advisory Group, 17/75 Lorimer Street Docklands, Victoria 3008, Australia*
[i] *Centre for Health Practice Innovation, Griffith University, Queensland 4222, Australia*
[j] *Centre for Online Health, University of Queensland, Brisbane, St Lucia, Queensland 4072, Australia*
[k] *Children's Health Queensland Hospital and Health Service, 501 Stanley Street, South Brisbane, Queensland 4222, Australia*
[l] *Nursing and Midwifery, Sunshine Coast Hospital and Health Service, Hospital Road, Nambour, Queensland, 4560, Australia*

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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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* Corresponding author.
E-mail addresses: M.Tallon@curtin.edu.au (M.M. Tallon), G.Kendall@curtin.edu.au (G.E. Kendall), l.priddis@ecu.edu.au (L. Priddis), Fiona.Newall@rch.org.au (F. Newall), jyoung4@usc.edu.au (J. Young).

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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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and care of patients and families in the healthcare setting was maintained. Searches were limited to research and review publications written in the English language. No time limit was set in order to allow for references that were relevant from a historical perspective. The search terms used during the searching process were variations of the following: Patient(s), family(ies), child/ren, p(a)ediatric(s); healthcare/chronic illness/serious illness; psychological/social/psychosocial/resources; stress/distress; barriers. Individual searches were initially conducted using healthcare, psychological, social, psychosocial, patient, child, and family. The terms healthcare, psychological, social, psychosocial, barriers were combined with AND, while the terms healthcare, patient, family, child; chronic/serious illness, were also combined with 'AND'. Following application of the exclusion criteria and removal of duplicates this total was reduced to 13 publications that were identified for inclusion in this review. The quality of the research evidence in the selected publication was graded from level one to level four and adapted from the National Health and Medical Research Council evidence hierarchy (Merlin, Weston, & Tooher, 2009). See Table 1.

Table 1

Summary of sourced literature examining barriers to addressing social determinants of health by families and healthcare providers.
Adapted from NHMRC (Merlin et al., 2009).

Author	Design, sample and location	Findings	Quality
Bradford and Rickwood (2014) Electronic psychosocial assessment tool: Concept development and identification of barriers to successful implementation.	Cross sectional cohort survey. n = 175. Young people 12–25 years. Australia.	A need for welcome and reassurance and questions that are clear identified by participants. Concerns about feeling judged. Concerns about confidentiality, time constraints, duty of care identified by HCPs.	Level III.3
Dilworth, Higgins, Parker, Kelly, and Turner (2014). Patient and health professional's perceived barriers to the delivery of psychosocial care to adults with cancer: A systematic review.	Systematic review 25 papers included	Patients need clear information about the role of psychosocial care as well as the services. Strategies needed to address interplay between individual, organizational and cultural factors are needed.	Level 1
Fagerlind, Kettis, Glimelius, and Ring (2013). Barriers against psychosocial communication: oncologists' perceptions.	Quantitative non-experimental design. n = 575. Medical healthcare providers. Sweden.	Older healthcare providers were more psychosocially orientated that those younger. Hospice more psychosocially orientated than university hospital setting. Barriers: Insufficient time, feedback, lack of support.	Level III.3
Gosselin, Crane-Okada, Irwin, Tringali, and Wenzel (2011). Measuring oncology nurses' psychosocial care practices and needs: results of an Oncology Nursing Society.	Cross sectional survey. n = 401. Nurses. USA.	Nursing perceptions about psychosocial issues differ. Barriers at individual, institutional, and community levels.	Level III. 3
Griffiths, Ewing, and Rogers (2010). "Moving swiftly on." Psychological support provided by district nurses to patients with palliative care needs.	Thematic analysis 6 focus groups Total participants: n = 53. Nurses. UK.	Psychosocial assessments occur informally. Avoidance behaviors are used when faced with psychosocial concerns.	Level IV
Guest et al. (2013). Implementing and evaluating a professional practice framework in child and family health nursing: A pilot project.	Comparative study following implementation of a practice framework. Pre- and post- test using survey. Nurses. Australia.	Improved levels of confidence and satisfaction following implementation. Deemed a quality improvement exercise.	Level III.3
Horwitz et al. (2007). Barriers to the identification and management of psychosocial issues in children and maternal depression.	Cross sectional study. Random sample n = 745 P Physicians. USA.	Identified barriers included a lack of time, waiting periods to access psychological supports. Organizational barriers	Level III.2
Hui Choi et al. (2012). The relationships of social support, uncertainty, self-efficacy, and commitment to prenatal psychosocial adaptation.	Non-experimental cross sectional correlation prospective study using a questionnaire. n = 550 women in late pregnancy. Hong Kong.	Four explanatory variables of psychosocial adaptation were identified as social support, uncertainty, self-efficacy and commitment to parenting.	Level III.3
Mitchell, Vahabzadeh, and Magruder (2011). Screening for distress and depression in cancer settings: 10 lessons from 40 years of primary-care research	Narrative review of research.	Both over and underdetection of psychosocial issues are problematic. Barriers to identification include low confidence, low skills, lack of time by HCPs. Patients are reluctant to get help, or disclose concerns. Somatic symptoms also present a barrier.	Level III.3
Nieto and Day (2009). Family Partnership Model as a framework to address psychosocial needs in pediatric cancer patients.	Summary of scientific literature on the psychosocial needs of pediatric cancer patients and their families. USA.	A need to move outside deficit orientated model. A need for cost effective psychosocial interventions.	Level IV
Rushton, Bruckman, and Kelleher (2002). Primary care referral of children with psychosocial problems.	Secondary analysis of child behavioral data collected 1994–1997. Sample: 260 health facilities USA, South America, Canada.	Referral for support with psychological issues is complex and varied and influenced by expertise, cost and availability.	Level III.3
Spiers, Parker, Gridley, and Atkin (2011). The psychosocial experience of parents receiving care closer to home for their ill child.	Qualitative case study design Sample: 22 interviews across four diverse pediatric health services. UK.	Parents who feel supported are more accepting of parental responsibility for care of complex medication and treatments at home.	Level IV
Weaver et al. (2016). Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review.	Integrative review of literature across four databases from 2000. Synthesis of 182 studies.	Cost analysis, social support, sibling care, communication approaches for decision making identified as shared priorities.	Level IV

Footnote: Strength of evidence: Level I – Systematic review of Level II studies, Level II – randomized controlled trial, Level III. 1 – A pseudorandomized control trial, Level III.2 a comparative study with concurrent controls; non-randomized; cohort; case-control. Level III.3. Comparative study without concurrent controls; historical control study; two or more arm single study. Level IV – Case series.

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Barriers to Addressing Social Determinants of Health by Families and Healthcare Providers

Many healthcare providers recognize psychosocial distress and emotional pain in their patients, but feel constrained within a health system where physical care is emphasized (Griffiths et al., 2010). This is also reflected among patients who focus on physical aspects of their health and believe that attention to psychological and social issues is not a priority (Dilworth et al., 2014). This is especially evident in situations where patients receive intensive medical care, such as that required following trauma (Bradford & Rickwood, 2014). Difficulties perceived by healthcare providers were found to be more complex and went beyond the healthcare providers' attitudes and qualities to include organizational and cultural features (Dilworth et al., 2014).

The acceptability of screening has been identified as critical in the assessment of emotional health problems in medical practice in recent decades (Mitchell et al., 2011). However, insufficient time, a lack of resources for taking care of potential problems, and a lack of appropriate tools to evaluate patients' psychosocial health were identified as barriers by doctors (Fagerlind et al., 2013) and similarly by nurses during clinical practice (Dilworth et al., 2014). In the same study, barriers to the identification and management of psychosocial issues in children with depressed mothers were identified by the physicians as a lack of time, resources and skills (Horwitz et al., 2007). Furthermore, relying on clinicians' unassisted judgements without infrastructure was identified as problematic as was the use of overly complex scales with low acceptability (Mitchell et al., 2011). A lack of time and resources were also identified as barriers to providing optimal psychosocial care in specialist settings (Gosselin et al., 2011). In the same study, survey analysis showed that over 80% of nurses perceived that patients had a mindset that psychosocial issues were not as important as medical care, and that patients experienced stigma and did not want to address psychosocial issues (Gosselin et al., 2011). However, these nurses were found to be divided on who was responsible for providing psychosocial care; 35% directed this to the nurse, 33% allocated this responsibility to social workers and for the remainder, responsibility was spread across other disciplines including physicians, pastoral care teams, and behavioral healthcare professionals (Gosselin et al., 2011).

Similar reservations were identified as a lack of confidence and skills by district nurses in the UK where most information was shared by ‘chatting’ while nurses indirectly assessed the needs of their patients. However, avoidance and blocking strategies were also identified as ‘moving swiftly on’ when their patients became distressed (Griffiths et al., 2010). A deeper understanding was sought in a study of nurses in a palliative care setting who believed they were ‘in tune’ with their patients' emotional feelings of hopelessness, but were in conflict between this and being part of the medically focused culture where emphasis continued to be placed on treatment (Nieto & Day, 2009).

Among children and families, difficulties were identified in the process of referral and management of psychosocial issues in a large international sample Child Behaviour Data across the US, Canada, and Puerto Rico where only 61% of the 650 families in need of psychosocial support were referred for additional support with a specialist (Rushton et al., 2002). Further, the referrals made were for behavioral problems, poor academic performance, and mental health symptoms of the child, whereas family-life stress or a lack of emotional or social resources, were not included. The study showed that the issues given attention were those that were clinically relevant to the child not the family (Rushton et al., 2002). This perspective was also shared among practicing physicians in a cross-sectional study where psychosocial issues were perceived to be behavioral problems and somatic symptoms of anxiety or depression in the child. Again, consideration was not given to other sources of psychosocial stress and strain such as a mother's depression or family hardship.

Conversely, in a palliative care setting psychosocial issues and support were found to be more focused on the family (Nieto & Day, 2009). A lack of attention to the perspectives of siblings and grandparents was noted along with an absence of the children's voices. Findings suggested marginalization in a hierarchical system or an assumed incapacity to provide meaningful insight (Weaver et al., 2016).

These findings suggest an approach to healthcare that is reductionist and dominated by attention to physical, rather than psychological and social, health outcomes and physical causal pathways to disease.

Discussion

The review of literature has identified that healthcare providers do recognize emotional distress experienced by patients, but they feel unable to address psychosocial issues due to constraints imposed by a healthcare system that emphasizes disease and treatment. Specific issues reported by doctors and nurses were the lack of time, the 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 and that there was little opportunity to talk about psychological and social concerns.

It is clear that the greatest barrier to addressing the social determinants of health in the pediatric context is the dominance of the ‘medical model’ of care. While family-centered care (FCC) has been popularized as the most appropriate model for guide pediatric nursing practice in countries, such as Australia, the United Kingdom, and Canada, in practice it means little more than one or other parent ‘living in’ with their child in hospital and taking an active role in providing routine care (Tallon, Kendall, & Snider, 2015b). As the title suggests, FCC implies that the whole family is the focus of nurses' attention. If FCC were to be practiced in this way, talking about the social determinants of health and psychosocial issues would be considered routine.

A growing body of research evidence from Canada and the United States supports the benefits of applying a family systems nursing (FSN) approach as an alternative to the medical model. In particular, the work of Friedman (1989), Knafl, Breitmayer, Gallo, and Zoeller (1996), Deatrick and Knafl (2003), Wright and Leahey (1990), and Bell and Wright (2015), all incorporate knowledge of social determinants of health as the basis on which to implement nursing interventions that result in improved emotional well-being and behavioral responses in patients and families living with serious and chronic illness (Östlund & Persson, 2014). A focus on the impact of illness on people's daily lives, rather than on the disease itself, directs attention to the psychological and social issues that concern families.

It is also clear that many healthcare providers believe that they lack the communication skills necessary to talk about psychological and social issues with families so as to effectively address the social determinants of their health. Nonetheless, the concept of therapeutic communication is well known to nurses and most other groups of healthcare providers. The application of skills in genuine enquiry and reflective listening are promoted in partnership models, such as the Family Advisor Model developed for pediatric practice in the UK by Davis (2002, chap. 4). The Family Advisor Model has reportedly improved coping and decision making by parents of sick children (Bidmead, Davis, & Day, 2002). Also in nursing practice, skills of therapeutic communication are embedded in models of care from FSN that are applied internationally, and support improved emotional health and confidence in caregiving (Bell & Wright, 2015; Wright & Leahey, 1994). In keeping with this, an integrative review by Östlund and Persson (2014) found improved self-efficacy in patients, parents and families, when empowerment was promoted through a reciprocal relationship between families and healthcare providers. In a recent study conducted in Australia, relational strategies were welcomed by 111 mothers who showed improved emotional wellbeing and caregiving as a result of a home visiting program (Fowler et al., 2012). In another example, the most successful interventions by nurses in a home visiting program for vulnerable families in a disadvantaged area in Sydney,

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Australia were found to be responses to maternal emotional needs (Stubbs & Achat, 2012).

Implications for Pediatric Nursing Practice

The full scope of pediatric nursing practice includes care of the child and family. The literature suggests that many nurses are not currently practicing to their full potential with regard to talking to families about psychological and social issues. It is a small step forward to identify this problem, however, a giant leap will be required to translate this knowledge and understanding into routine clinical practice. We need to move our focus away from the barriers to this happening towards enablers of this. In an environment where practice standards are increasingly used to optimize safety and quality of care, there is little time to loose. For example, the Australian Commission of Safety and Quality in Healthcare has stated ten national standards for quality healthcare. National Standard Two is 'Partnering with Consumers' (Australian Commission of Safety and Quality in Healthcare, 2011).

One important aspect of partnering with consumers is focusing attention on their needs; acknowledging the distress they experience and the level of resources they have access to. We believe the most appropriate 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 encouragement of mentorship in the provision of compassionate family-centered care.

Conclusion

The social determinants of health are pervasive in both developed and developing countries across the world. There may be a tendency for some pediatric nurses to believe that structural factors that influence the health outcomes of children and their families, such as unemployment and low income, are beyond their scope of practice. While it is not possible to solve all of the world's problems, there is a great deal pediatric nurses can do to alleviate the distress experienced by those who are struggling to mobilize their resources and those who lack resources, altogether. As one advanced practice nurse put it, 'It's about having empathy for our families. They feel that no one else is going to understand the issues they have more than we are. While we may not be able to solve their problems, it helps if we can *really* listen to what they are telling us'.

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