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Involving Parents in Managing Their Child's Long-Term Condition—A Concept Synthesis of Family-Centered Care and Partnership-in-Care¹

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Background Fostering effective engagement, collaboration and empowerment are central to supporting parents caring for children with long-term conditions.

Methods: A concept synthesis was undertaken to identify the shared antecedents and attributes underpinning models of family-centered care and partnership-in-care.

Results: Thirty studies were reviewed; antecedents of models related to unclear roles, entrenched professional practices, and lack of guidelines supporting their implementation; with central attributes being building trust, listening to parent concerns and valuing parents' knowledge of their child.

Conclusion: The key attributes are outlined in a practical framework of involvement which may promote parent–professional collaboration for families of children with long-term conditions.

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INTERNATIONAL HEALTH POLICY advocates that patient-centered care is embedded into care delivery and that patient–professional interactions are participatory and collaborative in nature (International Alliance of Patients' Organizations, 2007). Actively involving parents in care decisions, and children and young people as appropriate, is particularly salient in the context of long-term conditions where the day-to-day management of care becomes primarily the responsibility of the family. Evidence suggests that caregiving such as providing medical and nursing interventions above usual parenting tasks is a significant feature of living with a child with a long-term condition for both fathers and

mothers (Cashin, Small, & Solberg, 2008; Smith, Cheater, & Bekker, 2013a; Wennick & Hallström, 2007). In order to manage their child's condition, parents need to; gain knowledge of the condition and treatments (Balling & McCubbin, 2001; Knafl et al., 2013; Nuutila & Salanterä, 2006); learn how to identify and respond to illness symptoms in their child (Smith, Cheater, Bekker, & Chatwin, 2013; Wennick & Hallström, 2007); and develop effective relationships with health professionals (Dickinson, Smythe, & Spence, 2006; Swallow & Jacoby, 2001; Swallow, Lambert, Santacroce, & Macfadyen, 2011; Swallow, Macfadyen, Santacroce, & Lambert, 2012). Many mothers and fathers living with a child with a long-term condition develop considerable expertise in managing their child's condition and want to work in partnership with health professionals (Smith, Cheater, Bekker, & Chatwin, 2013; Swallow et al.,

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2011; Swallow et al., 2012). Consequently parents expect care to be negotiated (Dickinson et al., 2006) and that they will be involved in care decisions (Fawcett, Baggaley, Wu, Whyte, & Martinson, 2005). However, parents do not necessarily want sole responsibility for care decisions (Balling & McCubbin, 2001; Smith, Cheater, Bekker, & Chatwin, 2013).

Patient-centered models of care such as family-centered care and partnership-in-care underpin the philosophy of children's nursing, and offer a way to involve parents in their child's care. However, these models have been criticized over the past decade as being espoused rather than enacted in every day practice (Coyne, 2013). There are several challenges for researchers and practitioners when conceptualizing the boundaries of families and family research; Knafl, Leeman, Havill, Crandell, and Sandelowski (2014) proposed a framework for setting the limits of the sphere of interest that provides direction to future researchers, with the goal of both supporting the overall quality of family research and efforts undertaken to synthesize research. Despite challenges in researching and operationalizing concepts relating to family-centered care, working effectively with families to enhance the care of children is central to many organizations that support health professionals working with children and families including; the Society of Pediatric Nursing (North America), National Association Paediatric Nurse Practitioners (North America), Association of British Paediatric Nurses (UK), Action for Sick Children (UK), and the Paediatric Nursing Associations of Europe (Europe).

This article presents a synthesis of family-centered care and partnership-in care, as these are the dominant concepts embedded within children's nursing in developed countries. Both family-centered care (Harrison, 2010; Hutchfield, 1999; Malusky, 2005; Nethercott, 1993) and partnership-in care (Coyne, 1996; Lee, 1999) have been analyzed as concepts in the past but require updating; synthesizing these concepts is a novel approach. The antecedents within these concepts in relation to involving parents in their child's care will be explored and an alternative framework for nurses working with parents living with a child with a long-term condition offered.

Background

A patient-centered approach to healthcare delivery where there is a mutually beneficial partnership between patients and health professionals is widely advocated within healthcare literature (Collins, Britten, Ruusuvaori, & Thompson, 2007). Furthermore, there is a broad consensus among policy makers and professionals that health professionals should enable patients to be involved in decisions about their own health care (Coyne, 2008; Entwistle, 2009). In child health care, the ideology of consumer involvement and patient-centered care is embodied within the philosophy of family-centered care and the partnership-in-care model. The family-centered care philosophy is consistent with the prevailing ideals of empowerment, respecting personal

autonomy and recognition of human rights (Mikkelsen & Frederiksen, 2011). Therefore, family-centered care is currently seen as the ideal system of care to structure the involvement of parents and families in children's health care globally (Shields, Pratt, & Hunter, 2006; Shields et al., 2012). Despite considerable research, patient-centered care and related terms such as family-centered care and partnership-in care remain poorly defined, and have different meaning across professional and patients groups (Franck & Callery, 2004; Mead & Bower, 2000; Petersen, Cohen, & Parsons, 2004; Power & Franck, 2008). In addition, the evidence-base relating to the impact of family-centered care and partnership-in care models on care delivery and parental satisfaction is weak, and outcomes are difficult to measure (Harrison, 2010; Mead & Bower, 2000; Power & Franck, 2008; Shields et al., 2012).

Family-centered care has been described as both a method of care delivery and a philosophy that value the vital role of the family in ensuring the health and wellbeing of the child, planning and delivering care around the whole family, working in partnerships with the family and across service provision (Shields et al., 2012). The Institute for Patient and Family-Centered Care (IPFCC) (2010, p1) defines family-centered care as, 'an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families'. Although some view partnership-in-care as a philosophy (Casey, 1988; Casey, 1995), there is increasing consensus that partnership is an attribute or central tenet of family-centered care (Coyne, 1996; Shields et al., 2012). The seminal work by Shelton and colleagues culminated in the development, of a framework for embedding family-centered care into practice (Harrison, 2010:336; Johnson, 1990; Shelton, Jepson, & Johnson, 1987; Shelton & Stepapel, 1995). The nine key elements of the framework helped guide this concept analysis, which are:

1. The family is a constant in the child's life;
2. Parent-professional collaboration should be facilitated across all levels of health care;
3. The racial, ethnic, cultural, and socio-economic and diversity of families should be respected;
4. Family strengths and individuality and respecting different methods of coping should be respected;
5. Complete and unbiased information should be shared with families;
6. Family-to-family support and networking should be encouraged and facilitating
7. Healthcare practices should respond to the child and family developmental needs;
8. Policies and practices should be adopted that provide families with emotional and financial support;
9. The design of health care should be flexible.

Operating within a model of family-centered care or partnership-in care requires nurses to shift from a position of care prescriber to one of collaborator, working in partnership with parents, and the child and wider family. Developing effective parent-professional partnerships has mutual

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