



Parents' and Health professionals' Views of Collaboration in the Management of Childhood Long-term Conditions

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ABSTRACT

Purpose: To explore how parents and health professionals view the concept and practice of collaboration in the management of childhood long-term conditions.

Designs and Methods: A qualitative research approach was adopted; sixteen parents and six health professionals participated in either individual or group interviews. Data analysis was underpinned by the Framework approach and involved an iterative process of reading the transcribed data, identifying and refining key themes until a coherent picture emerged.

Results: Two main concepts were identified: *expectations of collaboration* and *mechanisms for collaboration*. Health professionals' expectations of collaborative practice were influenced by their knowledge, experience and relative objectivity. They used relationship building with families as a key strategy for collaboration. Parents' expectations of collaboration varied and appeared to be influenced by their experience of living with their child's condition. Parents' needs were often unmet, particularly in relation to support with coordinating or accessing care on behalf of their child. Parents' strategies included resilience, assertiveness, determination and battling for what they needed.

Conclusion: Parents and professionals valued collaboration as a concept but differed in their expectations of collaborative practice and adopted different mechanisms to foster meaningful collaboration. A better understanding of the unique needs and experiences of parents of a child with a long-term condition is key to developing positive collaborative practice.

Practice Implications: Collaborative practice could be enhanced by health professionals' being more responsive to the full range of parent support needs, and being more pro-active about helping them work with the complexities of care systems.

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Current health policies within westernised societies promote models of service and care delivery based on person-centeredness (Moore et al., 2017; Santana, Manalili, Jolley, Zelinsky, & Lu, 2018; Wolf et al., 2018). Person-centered care prioritises patient need over service needs and promotes a collaborative approach in the way health professionals engage with, and involve, patients in care and care decisions (International Alliance of Patients' Organizations, 2007). The conceptualisation of care that is collaborative in nature is associated with a range of models and frameworks including: person-centered care (Moore et al., 2017; Starfield, 2011; Wolf et al., 2018), patient-centered care (Fox & Reeves, 2015; Kitson, Marshall, Bassett, & Zeitz, 2013) family-centered care (Coyne, 2015; Shields et al., 2012), child-centered care (Carter, Bray, Dickinson, Edwards, & Ford, 2014; Ford, Campbell, Cater, & Earwaker, 2018), negotiated care (Polaschek, 2003) and shared decision-making (Elwyn & Charles, 2009; Land, Parry, &

Seymour, 2017). Despite a lack of conceptual clarity and application in practice, collaborative approaches to practice have the potential to improve patient or family outcomes by valuing and incorporating their experiences and expertise into care and care decisions (Fix et al., 2018; Grocott & McSherry, 2018; Kitson et al., 2013; Kuo et al., 2012; Rathert, Wyrwich, & Boren, 2013; Shields et al., 2012; Smith, Swallow, & Coyne, 2015). Collaboration is particularly salient in the context of people living with a long-term condition. Managing long-term conditions depends on the negotiation of a mutually beneficial partnership between patients (and families as appropriate) and health professionals (Collins, Britten, Ruusuvaori, & Thompson, 2007; Entwistle, 2009; Smith, Swallow, & Coyne, 2015) that fosters collaborative decisions and care management (Kitson et al., 2013; O'Grady & Jadad, 2010).

Notwithstanding recent debates suggesting a model of child-centered care that promotes the active agency of children in care decisions (Carter et al., 2014), when the patient with a long-term condition is a child, the partnership with health professionals is typically family-focused. While children have the right to be involved in all decisions

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that affect them (United Nations, 1989), parents are likely to be both advocates and the primary care giver for their child and will play a key role in negotiating their child's care (Boshoff, Gibbs, Phillips, Wiles, & Porter, 2016). While the term parents will be used through this article, for some children the person with parental responsibilities, such as grandparents or foster carers, may not be their biological parents. The focus of this article is parent – professional collaboration in the context of the care of children with long-term conditions. Drawing on the principles of family-centered care a study exploring the collaborative care of children with long-term conditions will be described and discussed.

Background

Family-centered care is widely espoused as a framework that promises care and service delivery is practiced in way that support individuals within their family unit. Core components of family-centered care are developing an effective relationship with the family, with health professionals working collaboratively with them when planning and delivering care (Kuo et al., 2012). However, family-centered care has been criticised as being somewhat aspirational because of poor conceptualisation of the concept and poor implementation in practice (Coynne, 2015; Shields et al., 2012; Smith, Swallow, & Coynne, 2015). Unsurprisingly, debates about the widespread commitment to family-centered care and how it may usefully guide practice ensue (Shields, 2015; Uniacke, Browne, & Shields, 2018). Furthermore, findings from two systematic reviews on family-centered care have highlighted a lack of evidence in terms of measurable outcomes to support its practice (Shields et al., 2012; Watts et al., 2014). The Institute for Patient and Family-Centered Care's (IPFCC) has proposed a widely accepted definition of patient and 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' (Johnson et al., 2008, page iv). The IPFCC definition is centered around four core concepts:

- *Dignity and Respect* - health professionals listen to and value patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care;
- *Information Sharing* - health professionals communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making;
- *Participation* - patients and families are encouraged and supported in participating in care and decision-making at the level they choose;
- *Collaboration* - patients, families, health professionals, and hospital leaders collaborate in policy and program development, implementation, and evaluation of health care service design and in professional education, as well as in the delivery of care (Johnson et al., 2008).

The IPFCC's interpretation of collaboration is broadly consistent with that of O'Grady and Jadad (2010), who define collaboration as:

'A process of engagement in which health professionals and patients work together...to understand clinical issues and determine the best course of action' (O'Grady & Jadad, 2010, page 1).

Thus, collaborative patient, child and family-centered care practice appear inextricably linked. However, child and family-centered care has greater relevance for child health practice because it moves beyond the care of the child by considering the needs of the family (Carter et al., 2014; Kuo et al., 2012).

In the context of working with children with long-term conditions and their families, collaboration is particularly salient as these children are primarily cared for at home, with parents taking responsibility for care decisions and delivering treatments (Kish, Newcombe, & Haslam,

2018; Smith, Cheater, & Bekker, 2015a). Furthermore, health professionals advocate working collaboratively with parents when deciding the best cause of action when planning and managing the child's condition (Smith, Cheater, Bekker, & Chatwin, 2015). Research focused on adult patients highlights that when collaboration works well it can increase a patient's involvement in care and treatment decisions, resulting in improved treatment adherence and satisfaction and trust in working with health professionals (Dwamena et al., 2012; Johnson, Ford, & Abraham, 2010; Melbourne et al., 2010; Westermann, Verheij, Winkens, Verhulst, & Van Oort, 2013). Although, there is a paucity of similar evidence in the child health setting (Shields et al., 2012), parents report wide variations in the quality of parent – professional relationships, with some parent perceiving that their expertise and contribution to care is not valued (Smith, Cheater, & Bekker, 2015b; Swallow et al., 2013).

A collaborative approach to healthcare delivery offers the opportunity to harmonise families' and professionals' viewpoints in order to shape healthcare interventions that address patient priorities, and is essentially patient and family-centered (Collins et al., 2007; O'Grady & Jadad, 2010). However, collaborative care brings many challenges, since health professionals and families may have widely varying expectations, experiences, expertise, and motivation to work collaboratively (Moore et al., 2017). Furthermore, collaborative practice will require health professionals to shift from a paternalistic approach to care delivery to one where the differing perspectives of parents and professionals are integrated, to improve a joint understanding of the child's condition that informs care planning and delivery (Smith, Cheater, Bekker, & Chatwin, 2015). A useful way to develop an understanding of collaborative practice is to consider the position of each party, in this study how parents and health professionals are involved in the collaborative process, as outlined in Fig. 1 (O'Grady & Jadad, 2010). Unlike reductionist models of care that are service and task oriented, collaborative models are more likely to have an increased emphasis on understanding individual or in the context of this study parent aspirations and experiences, and to foster a mutual understanding between parents and health professionals about illness management (Haidet et al., 2008; O'Grady & Jadad, 2010). In the context of childhood long-term conditions it is likely that as parents become skilled and experienced in providing care for their child they shift from a passive to more active position when collaborating with health professionals.

In summary, collaboration as a concept seems to be widely supported as a component of family-centered care but there is a lack of clarity about what collaborative practice means to parents and health professionals. Therefore, the aim in this study was to explore how parents and health professionals view the concept and practice of collaboration in the management of children with long-term conditions. The specific objectives were to:

- Appraise the extent of a shared understanding of collaboration in the care of children with long-term conditions between parents and professionals;
- Gain insights into parents' perceptions and experiences of being involved in care and care decisions;
- Gain insights into healthcare professionals' perceptions and experiences of involving parents in care and care decisions;
- Make recommendations to inform how health professionals could respond to parent expectations to enhance collaborative practice in relation to the care of children with long-term conditions.

Methods

Design and Participants

A qualitative research design was adopted, with data collected from individual and group interviews. A qualitative approach was appropriate because, first qualitative methods are suitable for exploring areas

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