This is a repository copy of *Parents' and Health professionals' Views of Collaboration in the Management of Childhood Long-term Conditions*.

Title

Parents' and health professionals' views of collaboration in the management of childhood long-term conditions

Authors

Dr Joanna Smith, Associate Professor Children's Nursing, School of Healthcare, Baines Wing, University of Leeds, Leeds e-mail: j.e.smith1@leeds.ac.uk

 Dr Sarah Kendal, Independent Mental Health Nurse Researcher

sarah.kendal.uk@gmail.com

Highlights

- Patient-centered and family-centered care are poorly defined concepts and not routinely embedded into every day practice;

- Effective parent-health professional collaboration may result in improved outcomes for children and their families;

- The nature of the parent-health professional relationship is key to developing positive collaborative practice;

- Families and health professionals differ in their expectations of strategies to work collaboratively.

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.

Current health policies within westernised societies promote models of service and care delivery based on person-centeredness (Moore et al., 2017; Santana et al., 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 et al., 2013) family-centered care (Coyne, 2015; Shields at al., 2012), child-centered care (Carter et al., 2014: Ford et al., 2018), negotiated care (Polaschek, 2003) and shared decision-making (Land et al. 2017; Elwyn, & Charles, 2009). 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; Kou, et al., 2012; Rathert, Wywich, & 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 et al., 2007; Entwistle, 2009; Smith, Swallow, & Coyne, 2015) that fosters collaborative decisions and care management (O'Grady, & Jadad, 2010; Kitson et al., 2013).

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 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 et al., 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 (Kou 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 (Coyne, 2015; Shields et al., 2012; Smith, Swallow, & Coyne, 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 IFPCC'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; Kou 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 (Smith, Cheater, & Bekker, 2015a; Kish, Newcombe, & Haslam, 2018). Furthermore, health professionals advocate working collaboratively with parents when deciding the best cause of action when planning and managing the child's condition (Smith et al., 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 et al., 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 et al., 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 Figure 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

5

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.

Figure 1: Positioning of collaborators (adapted from O'Grady & Jadad, 2010)

Perspective	Heath professionals position	Parents position	Direction of knowledge	Purpose
Paternalistic	Directive	Passive	One way: Health professional – parent/carer	Compliance of patient
Autonomous	Receptive	Directive	One way: Parent/carer - health professional	Compliance of heath professional
Shared decision-making	Informative	Informative	Two way exchange	Equity in decision making process
Collaborative	Supportive	Proactive	Building knowledge: shared learning & exchanging information	Optimal action plan to improve health

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 of healthcare where evidence is limited. Second, as the study aim was to explore the meaning of parent-professional collaboration, an approach was needed that supported participants to share their experiences and perceptions of collaboration.

Email and telephone calls were used to identify a sample of parents and health professionals involved in the care of children with long-term conditions. Individuals and parent support groups in the North of England were approached to access parents, and professional contacts to target professionals with experience of working with families where a child has a long-term condition. Some of the health professionals were recruited from a Children's Hospital through their global communication systems. The sample consisted of 22 participants: 16 parents of a child with a long-term condition and 6 health professionals.

Data Collection

Individual interviews were undertaken with six mothers of children with a long-term condition and six health professionals by telephone or face-to-face at a location convenient to the participant depending on their preference. An interview topic guide was used that focused on inviting participants to share their experiences and opinions of collaborative practice, developed from previous studies undertaken by JS (Smith, Cheater, & Bekker, 2015a & b), outlined in Figure 2. In addition to the individual interviews, facilitated discussions with a peer support group (seven mothers and three fathers) run by and for families of children with Type 1 diabetes, who had not participated in the individual interviews, were undertaken; the data consisted of field notes recorded during and immediately after the discussion. Working in groups of three to four participants, four sheets of paper were placed at each table. Each sheet had one of the four preliminary themes headings (Figure 3), which were used to structure the discussion. Asking the blue-sky question (Figure 2) concluded the group discussion. As data analysis approached its final stage, the group were also invited to comment on the core concepts (Figure 3), as way of member checking to enhance the credibility of the findings (Birt et al., 2016). Recorded telephone interviews were transcribed verbatim and field notes were word-processed promptly while data could be easily recalled.

Figure 2: Topic Guide for interviewing

---

1. *Open question*

What do you think being involved/ involving parents in care and care decisions means?

2. *Guiding questions*

How much do you feel you are involved/involve parents in the care of their /your child?

Can you explain how health professionals/you identify and listen to your /parents concerns?

Do you have/facilitate opportunities to ask questions? How does this happen?

How important do you feel it is for yourself/parents to contribute to care decisions?

What do you think are the advantages and disadvantages to parents being involved in care and care decisions?

3. *Blue sky question*

In an ideal situation what do you think would help to ensure effective collaboration between parents and health professionals?

Data analysis

The Framework approach was used to analyse and identify themes within the data (Spencer et al., 2014; Smith, & Firth, 2011). The analysis consisted of a series of systematically applied stages, beginning with transcription of the recorded data and field notes, and reading and re-reading of the transcribed data to enable the researchers to become familiar with the data. Initially analysis was undertaken independently; debating and challenging individual assumptions resulted in a shared understanding of the data. This process culminated in developing a list of nine 'categories' from participants' accounts, which was used to organise and sort all transcribed data. Once all data extracts were incorporated into the category list, categories were reordered and grouped together into preliminary themes. At this stage the parent support group was asked to discuss the preliminary themes (Figure 3), as previously described, and offered an opportunity to explore with the group ways to enhance collaborative processes between parents and health professionals. This was an essential stage in refining initial thoughts and resulted in the preliminary themes being reviewed and refined. Finally, once a cohesive account was developed consideration was given to how the themes interlinked, and how collaboration operates in every-day practice, this resulted in the development of the core concepts, the final stage of Framework approach (Spencer et al., 2014). Figure 3 illustrates the process of moving from content categories, derived from the transcribed data, through to developing the core concepts. The parent group, as previously described, confirmed the core concepts.

Figure 3: Illustration of the process of moving from categories to core concepts

Content categories	Preliminary themes (presented to the parent support group)	Final themes	Core concepts
Unsure	Working with complexity	Drawing on health professional expertise	
Doing my best			**Expectations about collaborative care**
Dealing with health professionals	Negotiating care	Uses condition and treatment knowledge, expertise and skills to inform care decisions	
Working with parents			
Expectations	Service focus verse family focus care	Build collaborative relationship	
Parents concerns			**Mechanisms for achieving collaborative care**
Identifying needs			
Strategies to manage the situation	Different priorities	Understand and work with parent expectations	
Support systems		Resilience	

Ethics

Ethical approval for the study was gained from the School of Heath Sciences research ethics committee, University of Huddersfield, United Kingdom (UK). In order to contact health professionals, local research and development approval from Leeds Teaching Hospital Trust, Leeds, UK was gained. Written consent was obtained from participants prior to undertaking the interviews, and all data were anonymised.

Results

The sample included 16 parents of children with a long-term condition and six health professionals (one health visitor, one paediatrician and four children's nurses). Two of the parents were also health professionals but shared their perspectives as parents. Two of the health professionals were also academics. Three parents and one health professional were male. The children and young people who were the focus of the care had an age range of 7-20 years. Their conditions included: anxiety disorder, hyperallergic condition, Type 1 diabetes, multiple disabilities and autism.

Analysis of the data highlighted differences between parent and health professional expectations of collaboration and the mechanisms required to achieve collaborative care in practice. Two core concepts and the associated themes that emerged from the analysis are presented in Figure 4.

Figure 4: Expectations of collaboration and mechanism to foster collaboration

Core Concepts	Health professional - themes	Parent - themes
Expectations about collaborative care	• Responsible to work collaboratively • Working with parents in managing the child's conditions child • Uses condition and treatment knowledge, expertise and skills to inform care decisions	• Drawing on health professional expertise • Valued and respected by health professionals • Good communication
Mechanisms for achieving collaborative care	• Build collaborative relationships • Understand and work with parent expectations	• Build collaborative relationships • Resilience • Using knowledge and experience to negotiate care

To maintain anonymity when presenting data extracts, parent examples are labeled 'P' with facilitated discussion group data labeled 'FDG', and health professional examples are labeled 'HP'.

Expectations about collaborative care

Both parents and health professionals expected to collaborate in care but had differing expectations and priorities. Parent narratives revealed they expected to have access to and support from appropriately knowledgeable and experienced health professionals. In the early stages of managing their child's condition they relied on professional support. However, the way health professionals communicated information did not always meet parent's needs. There was a common experience of what parents in the facilitated discussion group called 'information overload'. Information overload was most marked following the initial shock and implications of their child's diagnosis, when parents heightened emotions hindered their ability to process information or contribute effectively to care discussions. However, there were similar accounts from parents who had developed knowledge and were gaining expertise in managing their child's care. All of the parents wanted expert guidance from health professionals and were frustrated if they perceived this level of support was not offered. Parents expected their concerns about their child to be taken seriously and wanted the best outcomes for their child and family. The following extract illustrates participants' perceptions of communicating with health professionals and drawing on their expertise:

> *'It was me, putting my foot down and saying right, this is not acceptable, this*
> *is not good enough, why is it up to me to tell you what to put my son on? Why*
> *should, why do I tell you when he needs more saline, when he goes on*

> *glucose, when he goes on insulin drips? That's not for me to decide, I*
> *shouldn't be making those decisions' (P6).*

In addition, for some parents the way in which health professionals communicated and the lack of information shared was unhelpful. One parent whose older child was receiving psychotherapy found the lack of communication from the service added to her concerns for her child's health and well-being:

> *'I don't need to know what happens (in the therapy sessions), but I do need to*
> *know if (my child) is getting better or worse' (P3).*

Health professionals were oriented towards developing collaborative relationships with parents and perceived they recognised the important contribution of parents to their child's care. Health professionals had empathy for parents, particularly in complex conditions, where some professionals may not have parents' depth of knowledge of the condition, but perceived they actively promoted working with parents in managing the child's care. The following examples highlight health professional views of their role in promoting collaborative care:

> *'Part of my role is to empower the parents, the families, the patients, to*
> *actually be managers of their own care... you have to almost let go, you have*
> *to give them the tools to be able to do it themselves' (HP1).*

> *'Parents and nurses bring two sets of expertise to the game. Parents are the*
> *ones who know their children really well… Whereas nurses come in with the*
> *theory, the skillset and the experience' (HP2).*

> *'It must get frightening when you feel you know more than the experts' (HP6).*

Parent accounts revealed they perceived that they shouldered the long-term responsibility of learning to manage their child's condition. Parents described a constant battle to access services, and assessments, diagnosis and treatment for their child, and expected health professionals to value and appreciate their commitment. Many perceived the entire process of living with their child's condition, and working with health professionals as unrelenting, exhausting and often impacting on partner and family relationships. Where their child had a particularly complex condition, poor communication between healthcare teams added additional to pressure of negotiating care across multiple specialist services. However, health professionals highlighted that they tried to understand and work with family's expectations. These contrasting views are highlighted in the following examples:

'…. willing to fight but it is exhausting and you can't fight all the time or everything…. marriage of 17 years broke as spent all her energy on (child)… each professional only looks at the condition (issues) relevant to them' (P5).

'We don't recommend that children that are boys with haemophilia play football. For a boy, that's huge, that's absolutely huge. So its about tailoring the treatment to keep them safe so that they can do what they want to do, within reason, and giving them the education, the skills and the knowledge to understand' (H4).

Across participant narratives, developing good parent-professional relationships was an expectation of working collaboratively. While for both parents and professionals effective communication was central to developing a good relationship, parents' accounts highlighted that at times communication was not a two-way exchange. Instead of being equal care partners they often felt judged and at times perceived their contribution to care was not valued. Parents expressed frustration that their knowledge and expertise were not valued, as highlighted in the following accounts:

'They didn't take into account anything I said at all' (P2).

'You'd feel like you were going in to get shouted at, like you were in school rather than … 'How can I help you?' it was, 'What have you done that for?'' (P6).

In summary, although health professionals explained the importance of parents' contributions to care, a common difficulty amongst parents was persuading professionals to view them as valid partners in care. Much of the care that parents described did not seem to be collaborative and often did not meet parents' expectations, though health professionals did appear to be sensitive to the tensions around collaborative practice.

Mechanisms for achieving collaborative care

The mechanisms that fostered collaboration were multi-faceted and similar for both parents and professionals, but they had different perception of how these operated in practice. Parent narratives indicated they were resilient when faced with setbacks, in their attempts to secure the best for their child. At times parents described tensions with health professionals if they challenged their professional judgment. However, parents with knowledge and experience in caring for their child with a long-term condition seemed better able to negotiate appropriate support. One parent described how her expert knowledge and skills in managing her child's rare condition enabled her to collaborate with health professionals and participate fully in a difficult treatment decision. Overall, parents perceived that they needed

to be resilient, tenacious, assertive and persistent when working with professionals, as highlighted in the following accounts:

> *'I kept ringing them, more than once a week sometimes-they were very nice and very good on the phone…I just to keep saying is there any cancellations, can we bring her in?' (P1).*

> *'You could see [my child] just getting ill-er and ill-er and thinner and thinner…I took him to the [GP] a few times and said look, he's still not right… can you do any other checks? 'No, no, we've done everything we can, he's fine.' …. Obviously, no he wasn't' (P6).*

> *'We had to make a decision to switch to Nasogastric feeding, so a total exclusion of food, and that had to be …discussed and agreed' (P4).*

It was evident across parent narratives that service-led rather than family-centric processes operated, which hindered parents' ability to engage with services and collaborate with heath professionals. Most parents, including those with professional insights into health and social care systems described learning to 'work' the system. In addition, parents did not find health professionals particularly supportive if they solely focused only on the child's symptoms, rather than viewing the child in a more holistic way and the needs of the family as a whole. Parents reported having to make the most of opportunities offered to them, but at times the way services engaged with them could be insensitive and upsetting. The following extracts highlight parent perceptions of services:

> *'You get two appointments a year with each specialist and you have to make them work for you. I arrive with a list of questions [but] not everyone has the skills or the determination to work that hard on getting the best out of the professionals (P5)'.*

> *'…I think the school education system ends up having to pick up quite a lot of the pieces, where health (systems) maybe should be doing more' (P2).*

> *'Saturday morning, I open this letter and there's this long report about how disturbed and disabled my son was……. its how you get treated and the lack of, the lack of support and even when you get it, you just have to just, its just like an endless battle' (P2).*

In contrast, health professionals described that they recognised the journey parents faced when living with a child with a long-term condition and often with complex health needs. Health professionals' emphasised that a key component of their role was to build

collaborative relationships with the family but appreciated that families may find relationship building challenging. Health professionals described a desire to understand parents' support needs, including the level and depth of information about the child's condition, and what role parents wanted to adopt in relation to care and decisions about care. However, both health professionals and parents revealed care teams often made assumptions about expecting parents to be active collaborators in care and care decisions, and the degree to which parents could remain objective about their child's care. The following extracts highlight differences in perspectives in relation to building a collaborative relationship:

> *'The starting point of our relationship with patients is collaborative [but] I think the [nature of the] collaboration changes, you know, as they go through their journey. Even before we look at collaboration, we have to establish…the extent to which they wish to be involved…but even that's a collaborative endeavour, because you have to work with them to find that out' (H3).*

> *'… the medical team might think they've got a relationship…but the family might not know how to engage' (H3).*

> *'There was the multi-agency meeting. So they said "oh it would be really helpful to show you what we've done, we've put [your child's] impairments, they blue-tacked it to the wall. I lost it, I just went take that down, I can't have that on the wall… they just took it off, oh sorry, gosh, yeah, it was a bit inappropriate, wasn't it'…. there was nothing positive about it… I said how upset I'd been in the tone of the (meeting), and she said well, you know, this is what we do, we've got limited time (P2).*

Although health professionals highlighted the importance of parents' contributions to care, a common challenge for parents was persuading professionals to view them as valid partners. Where a child had multiple health conditions, parents struggled to coordinate, attend and make best use of appointments with multiple specialist services. Interestingly, the only community-based health professional who participated was particularly sensitive to the challenges families faced in relation to engagement with multi-disciplinary and multi-agency teams. Other than this, there was scant evidence of health professionals acting as parent advocates, except in a general sense of care facilitation. However, one of the specialist nurse professionals, whose practice revolved around individual appointments, perceived that a key worker model ensured a clear point of contact for families over time:

> *'…. if it wasn't for a key worker, how would you try and work collaboratively, I'd be pushed to say that that was, that was doable…The keyworker is so*

important, because you're working with these families for sometimes eighteen
years' (H3).

Parents' accounts highlighted that they valued and benefitted from the support and advice from experts and were disappointed when they perceived the best level of expertise was not available to them. In these instances, parents described that they had to be assertive and used their knowledge and experience to ensure they received the care they expected. For example, one parent noted that their child was not being reviewed by the specialist leading the service and highlighted this level of care was expected:

'I actually mentioned two years down the line, I said how come my Consultant
is (name), yet I've never even seen him and it was only then, funnily enough,
the next one (appointment) I had was with (consultants name)' (P6).

Some participants from the family support group were emphatic that their experience of care was positive; while others highlighting that the same service did not value their contribution to care or health professionals did not seem willing to work collaboratively. In many ways this illustrates that each family is unique in terms of their expectations of services and the mechanisms they employed when working with health professionals. Yet, across parent narratives, they described a desire to build effective relationships with health professionals. Parents described that they strove to work with, not against, health professionals but where expectations were not matched by experiences, the relationships at times could become adversarial. Some parents emphasised their responsibility to building effective relationships with health professionals. In contrast, others reported that health professionals were not proactive in working in a way that fostering collaborations. The following extracts highlight contrasting accounts of engaging with health professionals:

'… we knew there were 'guidelines' and 'model' care but service 'fell short' and we
wanted the 'best'. It was the overall 'ethos' of care that was not right… we moved to
another centre to change services' (P7, FGD).

'You have to be adaptable and work with services' … 'work with not against doctors
and nurses' (P8 & 9, FGD).

'They've sort of softened up a bit … its more like what can we do to help you
now…a year ago, it definitely didn't feel like that. I used to dread the three
month checks because I just knew I'd get a rollicking' (P4).

'She used to ask about family, not just the child, so how are you, have you got
enough support, what's going on, you know' (P2).

In summary, the data suggests that health professionals' focus was on relationship building was a key mechanism for facilitating collaborative care. However, parents' focus was on doing whatever was necessary to access the best services for their child, which often involved developing resilience to obtain the services they perceived would best meet their child needs. Ultimately, they wanted to become knowledgeable about their child's long-term condition and experienced in providing care. There was evidence that when a family's needs were acknowledged, parents felt more positive about their relationship with health professionals.

Collaborative care: the need for an individualised approach

The final stage of the Framework approach involves making connections with and, if appropriate, expanding existing knowledge (Spencer et al., 2014). Two core concepts of 'expectations about collaboration care' and 'mechanisms for achieving collaborative care' that emerged from the analysis are fluid constructs. The study findings suggest that health professionals could consider strengthening their sensitivity and responsiveness to the changes in parent support needs. In the context of working with families, the O'Grady and Jadad's framework (2010) (Figure 1) would position the parent as moving from relative passivity to proactivity, with a health professional moving from a directive to a more collaborative approach, as both become attuned to each others' roles in the collaborative process. In contrast, understanding the fluid nature of the parent and health professional relationship appears to be key to developing positive collaborative practice, as illustrated in Figure 5. However, it is likely that parents and health professionals do not move along the phases of the relationship in a linear fashion; contexts and family needs fluctuate, and parent-professional relationships are rarely static.

Figure 5: Fluid relationship between parent and health professional

Phase of the relationship	HPs position	Parent position	Behaviour	Purpose
Parent/ career overwhelmed	Directive, supportive	Wants information but may not be processed Uncertainty Grieving	Parent provides narrative of their child's condition Health professional provides information, advice and support	Immediate management of long-term condition Establish processes for long-term engagement with services
Learning how to collaborate	Receptive, present, supportive	Learning how to manage their child's long-term condition	Parent asserting self as expertise and confidence building Health professional advising, supporting, negotiating	Sharing in care decision, moving towards equality of power
Collaborative	Available, supportive	Managing their child's long-term condition with access to advice and support	Parent supported to choose how they want to work with health professionals	Collaborative practice

Discussion

The study findings have highlighted how parents and health professionals perceived and experienced collaboration in the context of children with long-term conditions. While there were some similarities between parents' and health professionals' views on how to achieve collaboration such as building collaborative relationships (Figure 4), there were key differences in relation to their thoughts on how collaboration operated in practice. A gap was identified between health professionals' perceptions that they facilitate collaboration, and parents' account that being true collaborators in their child's care was difficult to achieve. This mirrors the literature on family-centered care where there is little consensus between parents and professionals about what family-centered care is, and how it is practice (Coyne, 2015; Kish, Newcombe, & Haslam, 2018; Kou et al., 2012). Furthermore, the inequality in the parent-professional relationship has been offered as a reason for parents' low expectations of family-centered care (Arabiat et al., 2018).

Discordance between the views of health professionals and parents about the meaning and purpose of collaboration has previously been highlighted (Espezel, & Canam, 2003; Swallow, et al., 2013). Arguably, collaborative practice is predicated on an unquestioned assumption that the health professional holds the balance of power in the relationship. In turn, the lack of shared understanding and commitment to implementing parent-professional collaboration may be contributing to the on-going professional domination of care and care decisions and therefore maintains the power imbalance. This resonates with the barriers to implementing family-centered care, where professionals find it challenging to shift away from tradition ways of working with parents (Coyne, 2015; Smith, Swallow, & Coyne, 2015).

Health professionals' accounts focused on engagement and partnership working, in contrast parents' accounts were dominated by struggling to access optimal care for their child. Health professionals expected to use their expertise to facilitate the best long-term condition management for the child and foster a collaborative relationship with parents. However parents' expectations had a different orientation; they wanted to be taken seriously and to have appropriate access to information, expertise and support. Therefore, whereas relationship-focused collaboration may be a primary goal for health professionals, while important may well be a secondary goal for parents. Effective communication (Arabiat et al., 2018) and building relationships on mutual respect and trust (Swallow, & Jacoby, 2001) have been identified as ways of improving parent perceptions that their support needs are being met. This is particularly relevant when considering the longevity of the parent-professional relationships in the management of children with long-term conditions.

The diverse needs and expectations of families can add to the challenges of embedding the practice family-centered care into care delivery. Changes in participants' views of collaboration over time were not explored; however evidence suggests parents' support needs change, as they learn to manage their child's condition and work with health professionals (Coffey, 2006; Smith, Cheater, & Bekker, 2015a). Overall, parents described a need for information early in the illness trajectory, and emotional and practical support compared to those who were more familiar with their situation and were in a stronger position to inform care decisions (Figure 5). As parents' confidence and competence in managing their child's long-term condition develops, they are more likely to shift towards a collaborative paradigm to care and care decisions, rather than one that is professionally dominated (Smith, et al. 2015). Therefore, developing a shared understanding of the meaning and purpose of collaboration in the context of children with long-term conditions is an essential stage in the development of collaborative practice.

Previous research has identified that parents develop considerable expertise in managing their child's long-term condition and expect to work collaboratively with health professionals (Balling, & McCubbin, 2001), they expect care to be negotiated (Dickinson, Smythe, & Spence, 2006), and they want to share care and care decisions with health professionals (Bowes et al., 2009: Dickinson, Smythe, & Spence, 2006; Smith et al., 2015). In order to facilitate parents' care-giving roles it has been suggested that health professionals move from a position of care prescriber to collaborator (Smith, et al., 2015; Swallow et al., 2013). However, the mechanisms of collaboration appear to differ between parents and health professionals. It is likely that health professionals take a longer view, based on their experience of the child's expected trajectories. In contrast some parents in this study seemed to concentrate on the present, perhaps not wishing to think further ahead. This may be a protective mechanism; parents' concerns and uncertainties about their child's future have been identified as a core component of living with a child with a long-term condition (Smith, Cheater, & Bekker, 2015b). Qualitative research exploring these differing perspectives of care priorities could further develop a shared understanding of collaborative practice.

Some of health professionals, in this study, highlighted the challenging journey that parents embark upon. This resonates with theories of grief and loss (Stroebe, Schut, & Boerner, 2017) and parents' accounts of living in the past while acquiring the skills to meet their child's immediate needs (Gibson, 1999). The study findings suggest that health professionals could develop skills in recognising and working supportively with parents who

will be faced with a range of emotions, putting aside any preconceived beliefs about parent expectations, and assumptions that parents expertise is a indication that they can be objective about their child's care.

Two health professionals were also academics, and perceived their theoretical knowledge influenced their views about collaborative practice. However, all of the health professionals appeared to have well-developed ideas about the theory and practice of collaboration, with their understanding about working with the parents' and changing roles and responsibilities evolving over time. The difficulties associated with implementing theory into practice have been widely debated; implementing concepts such as collaboration into every day practice will continue to be challenging if there is both an organisational and professional culture of paternalism and priority is given to health professional care goals (Moore et al., 2017). This professional dominated conceptualisation of collaboration potentially hinders the flexibility in its application to practice across individuals and families, and health settings. However, the historical documentation of the mothers' movement in the UK and successful campaigning to ensure nurses work with parents, rather than exclude them (Connell & Bradley, 2000), illustrates the potential of parents to drive collaboration.

Although collaborative practice can be embraced and valued as a key priority of the organisation and the multidisciplinary team, true collaboration will only occur if health professionals take responsibility for creating patient and family partnerships (Johnson, Ford, & Abraham, 2010). In relation to involving parents in care of a child with a long term condition, key collaborative processes have been identified as developing effective parent-professional relationships, negotiating with parents the level of support required, and ensuring transparency of participatory processes (Smith, Swallow, & Coyne, 2015). What appears to be lacking is an understanding of what skills are required for both parents and health professionals, and the development of practical tools to support collaborative practice. Santana et al. (2018) offer a useful framework of structure, process, and outcomes that could be relevant. The framework makes a connection between the individual/ family and the systems of healthcare delivery. The processes required to embed collaborative care into health practice including addressing organisational values and measuring and monitoring patient/ family reported outcomes (Santana et al., 2018). Again, further research to determine parent and indeed child outcomes in relation to measuring collaborative practice would be useful.

Shifting from a passive to active parent - professional relationship is essential for

collaborative care to operate in practice (Fox, & Reeves, 2015). O'Grady and Jadad (2010), describe a patient axis of passivity to proactivity and a health professional axis from directive to supportive, as presented in the adapted version for parents (Figure 1). The study reported in this article builds on this and suggests that the development of effective collaboration between parents and professionals is a process of continuous adjustments to changing needs and not simply a question of progressing smoothly in one direction. The fluidity of the relationship between parent and health professional, presented in Figure 5, emphasises that collaborative practice must be flexible. Importantly, health professionals should accompany parents on their journey and be sensitive and responsive to their changing support needs.

The absence of advocacy processes in participants' accounts was noticeable, with the obvious exception of parents advocating for their child. Key messages from parents were that appropriate care is not accessed without a struggle, suggesting health professionals should be willing to advocate and be proactive on behalf of parents, particularly as many families may not raise concerns. Collaborative practices could result in improved access and co-ordination of care by supporting parents to interpret and navigate care systems especially for children with multiple disabilities who are in the care of multiple teams.

Study strengths and limitations

Although the sample was obtained from a range of sources, it was primarily a sample of convenience and may reflect participants who valued collaborative practice. All health professionals in this study were interested in collaborative care and did not necessarily represent the views of their professional groups. Equally, parents who shared their views had no reason to be objective about their experiences, although the parents who were also health professionals made specific references to current pressures within UK health systems.

Although data analysis was undertaken initially independently and then together, we did not use external peer checking. However, the Framework approach is a robust method to analysis of qualitative data and enabled us to identify credible core concepts and sub themes that were validated by the parent/carer support group. The core concepts offer some clarity to help develop the theory and practice of collaborative working in the context of care of children with long term conditions.

Conclusion

This article explored the question of how parents and health professionals view the concept and practice of collaborating when caring for children with long-term conditions. Collaboration is complex and multi-faceted, with parents and professionals having different priorities but both focused on ensuring the best health outcomes for the child. To our knowledge, while recognising mothers have driven many of the changes relating to being involved in their child's care, the concept of collaboration in healthcare appears primarily constructed by professionals; models or frameworks of collaboration must be been driven by both the family and health professional perspectives. Parents want and strive to develop a collaborative relationship with health professions as a means of securing the best services and care for their child, but face uncertainties about their role in the relationship. Developing a shared understanding of the meaning and purpose of collaboration when supporting children with long-term conditions and their families is an essential stage in the development of collaborative practice.

Health professionals in the study emphasised that parents bring detailed expertise about the child to the partnership but health professionals may find it challenging to incorporate parents' knowledge to inform clinical decisions. This may be a result of tensions that exists for health professionals such as wanting to value individual choice and contribution to care, while avoiding risk, and working within professional and legal frameworks of accountability and maintaining their professional reputation. Further exploration of the key tenets of collaborative practice such as listening, and valuing the individual, could directly improve outcomes for families. This could represent a shift from evaluating outcomes from a clinical assessment of the child to evaluating signs of improvement in communication, sensitivity and power differentials between health professionals and parents.

Acknowledgements

References

Arabiat, D., Whitehaed, L., Foater, M., Shields, L., & Harris, L. (2018) Parents' experiences of family-centered care practices. *Journal of Pediatric Nursing, 42*, 39-44.

Balling, K., & McCubbin, M. (2001) Hospitalized children with chronic illness: parental caregiving needs and valuing parental experience. *Journal of Pediatric Nursing*, 16, 315-326.

Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016) Member checking: a tool to enhance trustworthiness or merely a nod to validation? *Qualitative Health Research, 26,* 1802-1811.

Bowes, S., Lowes, L., Warner, J., & Gregory, J.W. (2009) Chronic sorrow in parents of children with type 1 diabetes. *Journal of Advanced Nursing, 65*, 992-1000.

Boshoff, K., Gibbs, D., Phillips, R.L., Wiles, L., & Porter, L. (2016) Parents' voices: 'why and how we advocate'. A meta-synthesis of parents' experiences of advocating for their child with autism spectrum disorder. *Child: Care, Health and Development, 42* (6), 784-797.

Carter, B., Bray, L., Dickinson, A., Edwards, M., & Ford, K. (2014) *Child-Centered Nursing: Promoting Critical Thinking*. Thousand Oaks, CA: Sage Publications Ltd.

Collins, S., Britten, N,. Ruusuvuori, J. & Thompson, A. (2007) *Understanding the process of patient participation.* In Collins, S., Britten, N., Ruusuvuori, J., & Thompson, A. (eds.) *Patient participation in healthcare consultations: qualitative perspectives.* Open University Press, Maidenhead.

Connell, J. & Bradley, S. (2000) Visiting children in hospital: A vision from the past. *Paediatric Nursing*; 12, (3), 32-5.

Coyne, I. (2015) Families and health-care professionals' perspectives and expirations of family-centered-care: hidden expectations and unclear roles. *Health Expectations, 18* (5), 796-808.

Coffey, J.S. (2006) Parenting a child with chronic illness: a metasynthesis. *Pediatric Nursing, 32*, 51-59.

Dwamena, F., Holmes-Rovner, M., Gaulden, C.M., Jorgenson, S., Sadigh, G., Sikorskii, A,. Lewin, S., Smith, R.C., Coffey, J., Olomu, A. & Beasley, M. (2012) Interventions for providers to promote a patient-centered approach in clinical consultations. *Cochrane Database of Systematic Reviews*, Issue 12.

Dickinson, A.R., Smythe, E. & Spence, D. (2006) Within the web: the family- practitioner relationship in the context of chronic childhood illness. *Journal of Child Health Care, 10,* 309-325.

Entwistle, V. (2009) *Patient involvement in decision-making: the importance of a broad conceptualization.* In Edwards, A., & Elwyn, G. (eds.) *Shared decision-making in healthcare, 2ⁿᵈ ed.* Oxford University Press, Oxford.

Espezel, H.J.E., & Canam, C.J. (2003) Parent-nurse interactions: care of hospitalised children. *Journal of Advanced Nursing, 44*, 34-41.

Elwyn, G., & Charles, C. (2009) *Shared decision-making: from conceptual models to implementation.* In Edwards, A., & Elwyn, G. (eds.) *Shared decision-making in healthcare, 2ⁿᵈ ed.* Oxford University Press, Oxford.

Fix, G. M., VanDeusen Lukas, C., Bolton, R. E., Hill, J. N., Mueller, N., LaVela, S. L., & Bokhour, B. G. (2018) Patient-centered care is a way of doing things: How healthcare employees conceptualize patient-centered care. *Health Expectations, 21*(1), 300–307.

Ford, K., Campbell, S., Cater, B. & Earwaker, L. (2018) The concept of child-centered care in healthcare: a scoping review protocol. *JBI Database System Rev Implement Rep,* 16(4), 845-851.

Fox, A., & Reeves, S. (2015) Interprofessional collaborative patient-centered care: a critical exploration of two related discourses. *Journal of Interprofessional Care*, 29 (2), 113-118.

Gibson, C. (1999) Facilitating reflection in mothers of chronically ill children. *Journal of Clinical Nursing, 8*, 305-312.

Grocott, A., & McSherry, W. (2018) The patient experience: informing practice through identification of meaningful communication from the patient's perspective. *Healthcare*, 6 (1), e1-14.

Haidet, P., O'Malley, K. J., Sharf, B. F., Gladney, A. P., Greisinger, A. J., & Street, R. L. (2008). Characterizing explanatory models of illness in healthcare: Development and validation of the CONNECT instrument. *Patient Education and Counselling*, 73, 232–239.

International Alliance of Patients' Organizations (2007) *What is patient-centre healthcare? review of definitions, 2nd edition*. International Alliance of Patients' Organizations, London.

Johnson, B., Abraham, M., Conway, J., Simmons L.A, Edgman-Levitan, S., Sodomka, P., Schlucter, J., & Ford, D. (2008) *Partnering with patients and families for patient- and family-centered heath care systems.* Institute for Patient- and Family-Centered Care, California, USA.

Johnson, B., Ford, D., & Abraham, M. (2010) Collaborating with patients and their families. *American Society for Healthcare Risk Management*, 29 (4), 15-21.

Kitson, A., Marshall, A., Bassett, K., & Zeitz, K. (2013), What are the core elements of patient-centered care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *Journal of Advanced Nursing*, 69, 4-15.

Kish, A.M., Newcombe, P.A., & Haslam, D.M. (2018) Working and caring for a child with chronic illness: A review of current literature. *Child: care, health and development*, 44 (3), 343-354.

Kuo, D., Houtrow, A., Arango, P., Kuhlthau, K., Simmons, J. and Neff, J., (2012) 'Family-centered care: current applications and future directions in pediatric health care', *Journal of Maternal and Child Health*, 16(2): 297-305.

Land, V., Parry, R., & Seymour, J. (2017) Communication practices that encourage and constrain shared decision making in health-care encounters: Systematic review of conversation analytic research. *Health Expectations*, 20 (6), 1228-1247.

Melbourne, E., Roberts, S., Durand, A.M., Newcombe, R., Legare, F., & Elwyn, G. (2010) Dyadic OPTION: Measuring perceptions of shared decision-making in practice. *Patient Education and Counselling, 83*, 55-57.

Moore, L., Britten, N., Lydahl, D., Naldemirci, Ö., Elam, M., & Wolf, A. (2017) Barriers and facilitators to the implementation of person-centered care in different healthcare contexts. *Scandinavian Journal Caring Sciences*, 31, 662–673.

O'Grady, L., & Jadad, A. (2010) Shifting from shared to collaborative decision-making: a change in thinking and doing. *Journal of Participatory Medicine, 8* (2), e13.

Polaschek, N. (2003) Negotiated care: a model for nursing work in the renal setting. *Journal of Advanced Nursing,* 42(4), 355-363.

Rathert, C., Wyrwich, M.D., & Boren S.A. (2013) Patient-centered care and outcomes: a systematic review of the literature. *Medical Care Research and Review*, *70* (4), 351-79.

Santana, M.J., Manalili, K., Jolley, R.J., Zelinsky, S., & Lu, M. (2018) How to practice person-centered care: A conceptual framework. *Health Expectations*, *21*, 429-440.

Shields, L. (2015) What is family-centered care? *European Journal f0r Person Centre Care, 3,* 139-144*.*

Shields, L., Zhou, H., Pratt, J., Taylor, M., Hunter, J., & Pascoe, E. (2012) *Family-centered care for hospitalised children aged 0-12 years.* Cochrane Database Systematic Reviews, Issue 2.

Smith, J., Cheater, F., & Bekker, H. (2015a) Parents' experiences of living with a child with a long-term condition: a rapid structured review of the literature. *Health Expectations, 18* (5), 1709-20.

Smith, J. Cheater, F., & Bekker, H. (2015b) Parents' experiences of living with a child with hydrocephalus: a cross sectional interview based study. *Health Expectations, 18* (5), 1709-20;

Smith, J*.*, Cheater, F., Bekker, H., & Chatwin, J. (2015) Are parents and professionals making shared decisions about a child's care on presentation of a suspected shunt malfunction: a mixed method study? *Health Expectations*, *18* (5), 1299-315.

Smith, J., Swallow, V., & Coyne, I. (2015) Involving parents in managing their child's condition - a concept synthesis of family-centered care and partnership-in-care. *Journal of Pediatric Nursing, 30* (1), 143-59.

Smith, J., & Firth, J. (2011) Qualitative data analysis: the framework approach. *Nurse Researcher*, *18* (2), 52-62.

Spencer, L., Ritchie, J., O'Conner ,W., Morrell, G., & Ormston, R. (2014) *Analysis in practice*. In Ritchie, J., Lewis J., McNaughton Nicholls, C., & Ormston, R. (eds.), *Qualitative research practice: a guide to social science students and researchers*. Sage Publications, London

Starfield, B. (2011). Is Patient-Centered Care the Same As Person-Focused Care? *The Permanente Journal*, 15(2), 63–69.

Stroebe, M., Schut, H. ,& Boerner, K (2017) Models of coping with bereavement: an updated overview / Modelos de afrontamiento en duelo: un resumen actualizado, *Estudios de Psicología*, *38* (3), 582-607.

Swallow, V.M. & Jacoby, A. (2001) Mothers' evolving relationships with doctors and nurses during the chronic illness trajectory. *Journal of Advanced Nursing, 36,* 755-764.

Swallow, V., Nightingale, R., Williams, J., Lambert H., Webb, N., & Smith, T. (2013) Multidisciplinary teams, and parents, negotiating common ground in shared-care of children with conditions: A mixed methods study. *BMC Health Services Research, 13,* 264.

Uniackle, S., Browne T.K., & Shields, L. (2018) How should we understand family-centered? *Journal of Child Heath Care*, *e1-10*.

United Nations (1989) *United Nations convention on the rights of the child*. Geneva, United Nations.

Watts, R., Zhou, H., Shields, L., Taylor, M., Munns, A., & Ngune, I. (2014) Family-centered care for hospitalized children aged 0-12 years: a systematic review of qualitative studies. *JBI Database of Systematic Reviews & Implementation Reports*, *12* (7), 204-283.

Westermann, G.M., Verheij, F., Winkens, B. Verhulst F.C., & Van Oort, F.V.A. (2013) Structured shared decision-making using dialogue and visualization: a randomized controlled trial. *Patient Education and Counselling*, *90*, 74–81.

Wolf, A., Moore, L., Lydahl, D., Naldemirci, Ö., Elam, M., & Britten N (2018) The realities of partnership in person-centered care: a qualitative interview study with patients and professionals. *BMJ Open, 7*, e016491.