
Article:

Smith, J orcid.org/0000-0003-0974-3591, Swallow, V orcid.org/0000-0001-8504-4704 and Coyne, I (2015) Involving Parents in Managing Their Child's Long-Term Condition—A Concept Synthesis of Family-Centered Care and Partnership-in-Care. Journal of Pediatric Nursing, 30 (1). pp. 143-159. ISSN 0882-5963

https://doi.org/10.1016/j.pedn.2014.10.014

Journal of Pediatric Nursing: Nursing Care of Children and Families
Special edition focussing on children, young people and families living with long-term conditions

Title:

Involving parents in managing their child's long-term condition - a concept synthesis of family-centred care and partnership-in-care

Running Title:

Involving parents in care

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Article Type
Review/ theoretical article

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This review has not received commercial funding

Key words: Family-centred care, collaboration, partnership, parent, child

Abstract

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-centred 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.

Introduction

International health policy advocates that patient-centred 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 care-giving 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 (Bailing & McCubin 2001; Knafl, Deatrick, Knafl, Gallo, et al., 2013, Nuutila & Salanterä, 2006); learn how to identify and respond to illness symptoms in their child (Smith, Cheater, Bekker & Chatwin, 2013b; 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 (Swallow, Lambert, Santacroce & Macfadyen, 2011; Swallow, Macfadyen, Santacroce & Lambert, 2012; Smith, Cheater, Bekker & Chatwin, 2013c). 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, 2007, Smith, Cheater, Bekker & Chatwin, 2013c).

Patient-centred 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 criticised over the past decade as being espoused rather than enacted in every day practice (Coyne, 2013a). There are several challenges for researchers and practitioners when conceptualizing the boundaries of families and family research; Knafl et al., (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 operationalising concepts relating to family-centred care, working effectively with families to enhance the care of children is central to many organisations 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 counties. Both family-centered care (Hutchfield, 1999; Nethercott, 1993; Malusky, 2005, Harrison, 2010) 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-centred approach to healthcare delivery where there is a mutually beneficial partnership between patients and health professionals is widely advocated within healthcare literature (Collins, Britten, Ruusuvuori & Thompson, 2007). Furthermore, there is a broad consensus amongst policy makers and professionals that health professionals should enable patients to be involved in decisions about their own health care (Entwistle, 2009). In child health care, the ideology of consumer involvement and patient-centred care is embodied within the philosophy of family-centred care and the partnership-in-care model. The family-centred care philosophy is consistent with the prevailing ideals of empowerment, respecting personal autonomy and recognition of human rights (Domenighetti, 1994). Therefore, family-centred 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, Zhou, Pratt, Taylor, Hunter, et al., 2012). Despite considerable research, patient-centred care and related terms such as family-centred care and partnership-in care remain poorly defined, and have different meaning across professional and patients groups (Franck & Callery 2004; Power & Franck, 2008; Mead & Bower, 2000; Petersen, Cohen & Parsons, 2004). In addition, the evidence-base relating to the impact of family-centred care and partnership-in care models on care delivery and parental satisfaction is weak, and outcomes are difficult to measure (Mead & Bower 2000; Power & Franck, 2008; Shields, et al., 2012, Harrison, 2010).

Family-centred care has been described as both a method of care delivery and a philosophy that values 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 (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-centred care (Coyne, 1996; Shields et al. 2012). The seminal work by Shelton and colleagues culminated in the development, of a framework for embedding family-centred care into practice (Shelton, Jepson, & Johnson, 1987; Johnson, 1990; Shelton, & Stepanel, 1995; Harrison, 2010:336). 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 at 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 needsf;
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-centred 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 benefits in that healthcare professionals rely on parents' knowledge of their child and on their co-operation with the delivery of their child's care (Mitchell & Sloper, 2001). Similarly parents' expectations of being involved in decisions about their child's care will be realised. However, Darbyshire's (1993) description of partnership-in care as 'one of paediatric nursing's most amorphous and ill-described concepts' (page 1672), remains relevant because recent evidence suggests that implementing family-centred care and partnership-in care remains challenging (Ladak, Premji, Amanullah, Haque, Ajani, et al., 2013; Macdonald, Liben, Carnevale & Cohen, 2012; Uhl, Fisher, Docherty & Brandon, 2012).

Nurses increasingly provide complex health care in rapidly changing contexts; as a practice focused discipline theories underpinning nursing have the potential to advance and inform professional practice (McCrae, 2011). Theories can guide both research and practice; therefore the challenge is to develop theory that links empirical knowledge with the aesthetic practice in a way that is meaningful for nurses and patients (McCrae, 2011). Although developing theory will add to the knowledge base of nursing, concept development has broader application, drawing on the way nurses evaluate the evidence that underpins care, and use frameworks and models to guide practice (Walker & Avant, 2011). Furthermore, concept development can bridge the gap between nursing theory and practice and is often a precursor to theory development. Concept development includes three overarching strategies (Walker & Avant, 2011), which differ in relation to purpose and the extent of the existing body of literature, briefly: concept synthesis is appropriate to draw together concepts to generate new ideas; content analysis is appropriate to clarify an existing concept, identify its underlying attributes and develop a precise definition of the concept; and concept derivation is useful to transpose and if necessary redefine concepts between settings or disciplines.

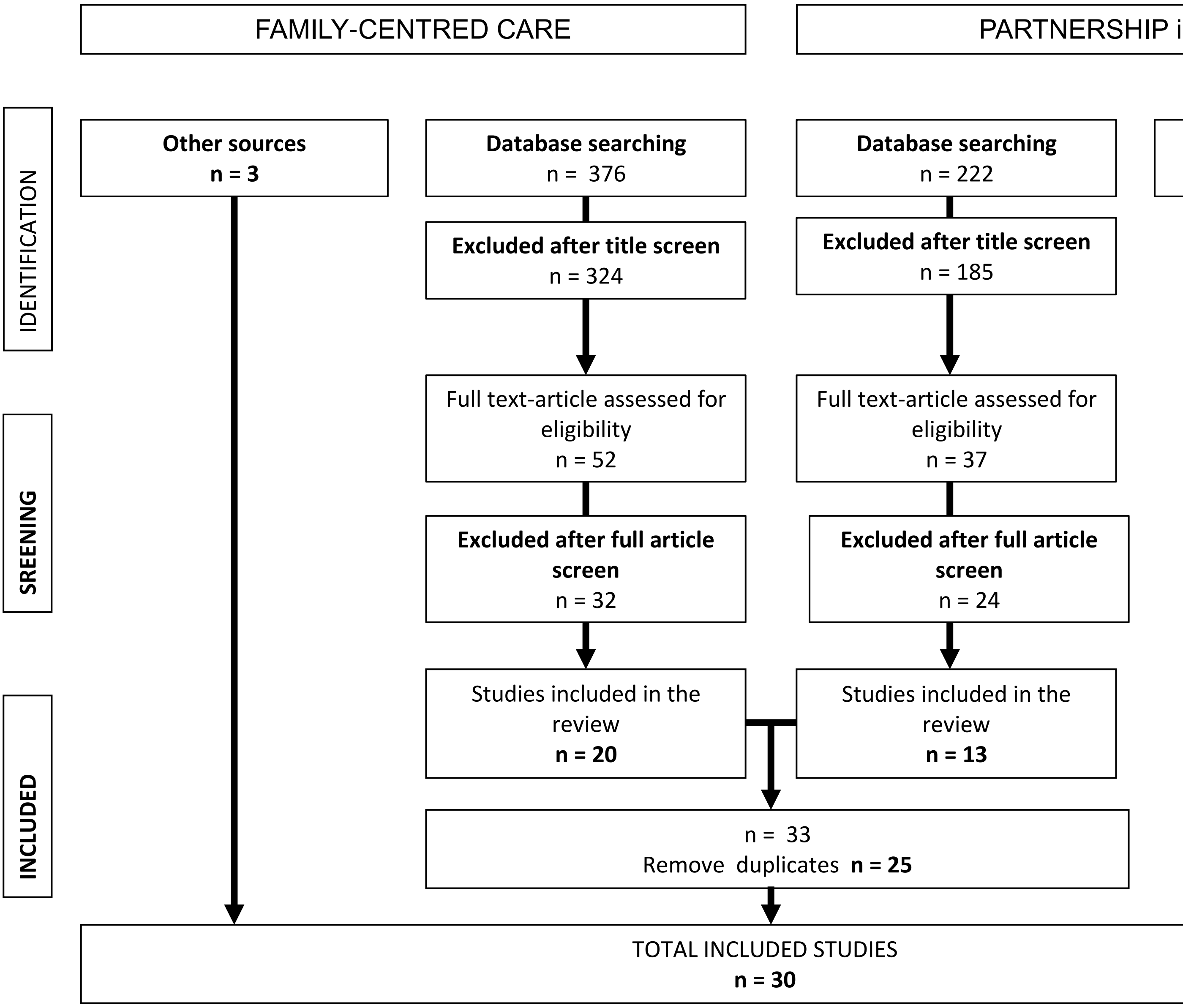
Lack of clarity and a common understanding of concepts such as family-centred care and partnership-in care have resulted in questions being asked about the extent to which these concepts are applied in practice (Coyne, 2013a; Franck & Callery, 2004). Actively involving parents in care decisions and working in partnership with parents appears particularly challenging, yet is essential in the context of children with long-term conditions as the day-to-day management of the child's condition is primarily the responsibility of the family. This concept synthesis aimed to identify the attributes of family centred-care and partnership-in care, summarise these and use them to create a practical framework for application by nurses working with families caring for children with long-term conditions.

Methods

Concept synthesis, which provides a means of examining empirical evidence from published literature or purposeful collected data or both to seek new insights and offer alternative ways of exploring a phenomenon, is useful in areas where existing concepts have little impact on practice (Walker & Avant, 2011). Concept synthesis was appropriate to meet our aim because family-centred care and partnership-in-care, which have become synonymous with children's and pediatric nursing, remain poorly defined and lack applicability to everyday practice. This concept synthesis involved reviewing primary research that had investigated family centred-care and/or partnership-in care; this enabled us to identify the antecedents and attributes of both these concepts, identify any overlap and combine their defining attributes in a novel way (Finfgeld-Connett, 2007). Studies were included if they had explored or evaluated parents', young peoples', children's' or nurse perceptions or experiences of family-centred care or partnership working. Studies were excluded if they evaluated satisfaction with family centred services or reported the development of instruments to measure family-centred care or partnership working. The concept synthesis was based on primary research published in English language, peer-reviewed journals between January 1999 and April 2014. Studies within this period are more likely to reflect contemporary health policy within developed countries, which has a greater emphasis on patient (or child and family) centred care, and working in collaboration with parents in relation to the management of long-term conditions.

Studies were identified by searching three health and social sciences data bases, Scopus, CINAHL, and BNI in May 2014. Key search terms were adapted to each data base but included terms such as: (child* OR famil* OR parent* OR nurs*) AND (family-centred care OR family centred care OR family centered care OR care by families) OR (partnership-in-care OR partnership in care OR parental involvement OR partnership). Additional studies were identified from personal correspondence with child health researchers Figure 1 outlines the process of selecting studies to include in the concept synthesis. Each of 509 titles retrieved were examined by JS and VS to establish if the article related to the focus of the review; after title screening abstract of relevant articles were assessed to establish if they met the inclusion criteria outlined above. Any uncertainties about the inclusion or exclusion of studies were discussed between all three authors to reach a consensus. Synthesis of concepts involved two stages, first extracting the key findings from each included study, and second mapping the findings to the key elements of family-centred care previously outlined (Figure 2). The antecedents (or foundations) and attributes (central components) that related to embedding models of family-centred care and partnership-in-care into every-day practice were drawn from the findings from the studies included (Figures 3 and 4) (Finfgeld-Connett, 2007; Walker & Avant, 2011). The attributes were then brought together into a framework of involvement that to could be used as a guide to help promote parent-professional collaboration for families of children with long-term conditions.

Figure 1: Flow chart of study selection process



Results

The concept synthesis was based on a critical review of 30 studies; studies were fairly evenly divided between exploratory research underpinned by qualitative methods and surveys including validated and purposefully developed questionnaires (Figure 2). Across studies a range of family members and health professionals participated. Studies were undertaken in diverse settings including community health services, hospitals, schools and social care settings, and captured both acute and long-tem conditions in childhood (Figure

2). Despite differences in study designs, participant groups and settings, there were similarities across findings, Figure 2.

Figure 2: Summary of included articles

Author	Study aim	Methods	Key findings
Beck et al. (2009) Denmark	A qualitative evaluation of a neonatal intensive care unit's remodelling project and impact on family-centred care	5 parents of infants cared for on 1 neonatal unit and 11 health professionals participated Data from 2 focus were analysed using constant comparative method of analysis	• Parents perceived that facilities influenced their experiences of being involved in care, and at times they felt that they were a visitor to their own infant • Environment (particularly large shared spaces with other families), hindered the 'family' unit' to develop and parents confidence in gaining the competencies required to care for their child • The design of the care environment can be a facilitator or a barriers to embedding family to care into practice
Bridgeman, (1999) England	Qualitative study that explored how children's nursing students develop an understanding of family-centred care	10 child branch nursing students (undergraduate and diploma students) participated and were recruited from 1 university Data from semi-structured interviews were analysed using Colaizzi's phenomenological analysis	• Family-centre care was described as a multi-faced concept incorporating interactions between the child, family and the nurse • Students reported that parents wanted to participate in their child's care particularly if they had a long-term condition but were often unsure about their role, and at times were unable to approach 'busy nurses' about participating in care • Students reported differences in individual nurse interpretation of family centred-care and nurses retaining role of primary care giver hinders development of family centred-care
Bruce et al. (2002) Canada	Survey of health professionals' perceptions and practices of family-centred care	483 nurses and allied health professionals recruited from 3 tertiary hospitals completed a 45 item questionnaire Data analysed using descriptive statistics and analysis of variance to evaluate participant characteristics and family-centred care practices	• Health professions rated providing emotional and financial support, and information as the most important element of family-centred care, but parent-professional collaboration was perceived as less important element of family-centred care • Incorporating elements of family-centred care such as involving and consulting with family about their child's needs, and designing services around the child's needs were difficult to implement in practice
Coyne, (2013a) Ireland	Qualitative study that explored families and health professionals perspectives and expectations of family-centred-care	18 children (acute illness and long-term conditions) and their parents/ 18 nurses participated and were recruited from 2 hospitals Data from interviews were analysed using principles of grounded theory	• Family-centred care was essential to reduce the distress when a child is admitted to hospital and improve the quality of care • Nurses endorsed family-centred care as central to care deliver but relied on parents to help with care resulting in unclear roles and boundaries • Family-centred care operated in the context of minimal collaboration or negotiation with parents

Author	Study aim	Methods	Key findings
Coyne et al. (2013b) Ireland	Survey of nurses perceptions and practices of family-centred-care questions reported)	250 nurses participated and completed the 47 item Family Centre Care Questionnaire (revised version) and were recruited from 2 hospitals Data were analysed using one-way ANOVA	• Family-centred care was recognised as being central to valuing each family's individuality and the family as a resources particularly providing information about unique needs of the child • Although nurses supported the philosophy of family-centred care they struggled to apply the principles of family-centred care into practice • Limitation in service provision and design hinder the delivery of family-centred care
Coyne et al. (2011) Ireland	Survey of nurses perceptions and practices of family-centred-care (findings from the two open ended questions reported)	250 nurses participated and were recruited from 2 hospitals 47 item Family Centre Care Questionnaire revised version included two open questions Data from the open questions were coded to develop themes	• Family-centred care viewed as ideal philosophy when caring for children but challenging to implement into everyday practice • Lack of organisational and managerial support hinders implementation of family-centred care • Identifying family needs, information sharing, shared decision making, facilitating parents to participate in care, inter-disciplinary collaboration were identified as central to the delivery of family-centred care
Coyne & Cowley, (2007) England	Grounded theory study that explored children's, parents' and nurses' views on participation in care in healthcare settings	11 children (acute illness and long-term conditions) / 10 parents / 12 nurses recruited from 7 hospitals participated Data from interviews were analysed using constant comparative method of analysis	• Current models and theories relating to partnership in care are outdated do not address the child's, parents' and nurses' experiences • Pendulum swung from excluding parent in care to expecting participation in care • Parents were concerned about demands on nurses, time available to spend with their child and build a relationship with their child
Davies et al. (2013) USA	Qualitative study using a grounded theory approach that explored bereaved fathers' perspectives of family-centred	60 fathers who experienced the death of child with a life limiting illness were participated and were recited from a range of palliative care settings Data from interviews were analysed using constant comparative method of analysis	• Elements of family centred care that fathers' valued in health professionals included: getting to know the family, talking about a range of issues which may not be related to their child's health needs, developing effective relationship, including parents as part of the team, having specialised knowledge to support family • Elements of family-centred care were not implemented consistently, which could result in sub-optimal care for the child
Fereday et al. (2010) Australia	Qualitative study that explored partnership in practice from the perspectives of parents of a disabled child	34 parents of a disabled child participated, and were recruited from a range of disability organisations Data from focus groups and individual interviews was analysed using thematic analysis	• Working in partnership with health professional was key to meeting their child's needs • Service provision did not always consider the family context and a lack of family centred care was identified; parents wanted professionals to have greater understanding of the family context • Valuing parents knowledge and contribution to care was often lacking • Parents did not always trust health professionals to deliver appropriate care at the same level of parents in their absence

Author	Study aim	Methods	Key findings
Ford et al. (2011) USA	Qualitative study that explored partnerships between parents and health professionals as a means of improving adolescent health	17 parents and 17 young people 51 health professionals were recruited from adolescent health clinics participated Data from focus groups and individual interviews were searched for common themes	• Parents-professional partnerships and relationships could be strengthened by building trust, listening to parent concerns, valuing parents knowledge of their child, improved communication about their child's specific health issues, more regular contact between health professionals • Young people perceived a need for greater be education for themselves and their parents about their health issues • Shared goal setting recognising the complexity of the parent / young person / professional triad
Holm et al. (2003) USA	Qualitative study that explored parental involvement and family-centred care in the diagnostic and treatment of childhood cancer	45 parents of children who had undergone treatment for cancer participated and were recruited from 1 hospital oncology centred Data from focus groups were analysed using thematic analysis	• Being an advocate for their child underpinned parents desire to be involved in their child's care • Being an advocate required having information about their child's condition and treatments; parents perceived that being actively included in care decisions facilitated their role as an advocate but this could be difficult in the intimating health care environment
Hughes, (2007) Ireland	Survey of parents' and nurses' attitudes to family-centred care	43 parents and 28 nurses participated and were recruited from 1 hospital Questionnaire data was analysed using descriptive statistics	• Parents were unsure of what was expected from them • Parents stayed with their child because they perceived that nurse s were busy and could not meet all their child's needs; however nurse perceived parents remained with their child to participate in care • Nurses perceptions of family-centred care and the need to empower parents was difficult to embed into practice
Koller et al. (2006) Canada	An ethnographic study exploring the experiences children, parents and health professionals when a child is admitted to hospital with a diagnosis of SARS	5 children, 10 parents and 8 health professionals' recruited from one hospital Data from interviews and patient records were analysed using open and axial coding	• Isolation procedures hindered effective communication, opportunities for information sharing and collaboration which are central to the provision of family-centred care • Imposed isolated and restricted contact between parents and their child caused tensions between parents and health professionals, and added to challenges of delivering family-centred care
Ladak et al. (2013) Pakistani	A non-randomized pre- and post-study assessing satisfaction with family-centred rounds	82 parents and 25 health professions were recruited from 2 paediatric intensive care settings in 1 hospital Data from 15 item parent and 7 item health professional satisfaction questionnaire were analysed using Wilcoxon rank sum test and t-test	• Parents perceived family-centred rounds serves as a means being involved in and a way of participation in their child's care decisions • Family-centred rounds improved communication and information sharing between parents and health professionals • Health professionals had mixed attitudes towards family-centred care in this context and some did not embraced family-centred rounds as a means of involving parents in care

Author	Study aim	Methods	Key findings
Lam et al, (2006) China	Qualitative study that explored parents' experiences of participation in care of hospitalised children	19 parents of a hospitalised child across range of conditions including acute illness and long-term conditions participated and were recruited from 1 hospital Data from semi-interviews were analysed using content analysis	• Parents stayed with their child to provide individualised day-to-day care and ensure their child was monitored because of perceived nursing workload pressures but was an unconditional aspect of being a parent • Parents perceived there could be greater sharing of information and offers of support from nurses to assist them in caring for their child • Nurses should recognise parents' role in caring for their child • Lack of facilities added to challenges of caring for a hospitalised child
Lee (2007), England	Qualitative study that explored what partnership in care means for children's nurses	10 nurses participated and were recruited from 1 hospital Data from interviews were analysed using framework approach	• Working in partnership with parents was viewed as central to caring for the child and family but participants reported negative attitudes towards partnering parents and difficulties implementing partnership; some nurse perceived parents lacked understanding of partnership working • Effective communication and negotiation skills, and valuing collaboration were identified central to working in partnership with parents
Macdonald, et al (2012) Canada	An ethnography study that explored family experiences of family-centred care in a paediatric intensive care unit	18 families participated, and were recruited from 1 paediatric intensive care unit Analysis of data from observation and interviews were undertaken for each family (cases) and across cases but method of analysis were not reported	• Operationalising family-centred care is a challenging; differences exist in the way family-centred care operated between families and professionals • Cultural change in relation to embracing family-centred care should not rely solely on better information but requires health professional to consider care practices that may inadvertently create barriers to implementing family-centred care and actively questioning whether care practice support family-centred care
MacKay & Gregory, (2011) Canada	Qualitative study that explored children's oncology nurses' experiences and perceptions of family-centred care	20 nurses participated and were recruited from a children's oncology centred at 1 hospital Data from semi-structured interviews were analysed using thematic analysis	• Nurse highlighted lack of hospital guidelines or policies regarding family-centred care, which hindered having a consistent approach to and embedding family-centred care in practice • Nurses highlighted requiring greater skills, knowledge and support systems to support the implementation of family-centred care
MacKean et al. (2005) Canada	Grounded theory study that explored parents' and health professionals' ' conceptualisation and experiences of family-centred-care	37 parents of children with long-term condition and 16 health professionals' including nurses participated and were recruited from 1 hospital Data from focus groups and individual interviews were analysed using constant comparative method of analysis	• Emphasis on family-centre care not useful to guide practice and difficult to embed into everyday care • Parents desired to work in collaboration with nurses and be part of care decisions • Parents' role and contribution to care not always valued • Lack of support for parents in relating to coordinating services and care delivery; systems make it difficult to navigating services

Author	Study aim	Methods	Key findings
Mäenpää et al. (2013) Scandinavia	Grounded theory study that explored family-school nurse partnership in primary school health care	22 young people / 19 parents / 20 nurses participated and were recruited across health and social services Data from focus groups, interviews, written narratives using were analysed using open and axial coding	• Meetings between the family and school nurse to ensure mutual exchange of information can be facilitated when parent attend school for health monitoring • Problem-based communication was identifies as way of working in partnership with parents which could be achieved by listening to the family, drawing on family expertise, responding to any family concerns and are central to working in partnership with families
McIntosh & Runciman, (2008) Scotland	Qualitative study exploring partnership working in the home care of children with special health needs	17 parents of children with special health needs and 20 health professionals' including nurses participated and were recruited from 1 hospital Data from interviews were analysed by coding data and searching for themes	• Nursing teams developed trusting relationships with parents through critical listening, sharing expertise and being empathic toward the child and family, advocacy was central to partnership working • Open and honest exchanges were a means enabling choice for parents and children, and ensured communication s were meaningful • Parents perceived that the complexity and changing health needs, particularly where immediate decisions were required, of their child meant that in some situations care negotiation was not in the best interest of the child
Murphy & Fealy, (2007) Ireland	Survey of nurses nurse practices and perceptions of family-centred care	149 nurses recruited from 2 hospitals completed a Family Centre Care Questionnaire revised version Data were analysed using one-way ANOVA	• There appears to be incongruence between knowledge and practices of family-centred care • Information sharing, shared decision-making, and facilitating parents to participate in care were often not part of every-day practice, but along with inter-disciplinary collaboration were identified as central components of family-centred care
Paliadelis et al. (2005) Australia	Qualitative study exploring the beliefs and practices of children's nurses about involving parents in the care of their hospitalised child	14 nurses participated and were recruited from 2 hospitals Data from interviews were analysed thematic analysis	• Nurses described allocating caring tasks to parents but perceived some caring tasks were better undertaken by nurses; there was a desire to protect parents from unpleasant procedures • Working collaboratively was perceived as a threat to nurse professional role • Although nurse perceived the power of heath professional's hindered collaborative working, practices were paternalistic reinforcing this imbalance of power • Barriers to implemented family-centred care included time constraints, lack of local guidelines and polices, lack of confidence or knowledge

Author	**Study aim**	**Methods**	**Key findings**
Pritchard-Kennedy, (2012) Canada	An ethnography study of school-age children with bleeding disorders perceptions of partnership roles in family-centred care of their chronic illness	8 children participated and were recruited from 1 children's hospital Data from unstructured interviews were analysed using constant comparative analysis and findings mapped to policy documents advocating family-centred care	• Children wanted to learn how to participate and become partners in their care, which could be achieved through health professionals listening and including children in care decisions • Children's views reflected policy guidance that advocates the need to involve children in care; yet children perceived that involvement was inconsistent and their involvement was not actively facilitated by health professionals
Raghavendra et al. (2007) Australia	Survey investigating parents' and service providers' perceptions of family-centred practice in a community-based, paediatric disability service	189 families and 145 professionals complete the measures of process of care, 20 item parent or 27 item version respectively, and were recruited from a wide geographical area Data were analysed using descriptive statistics; associations between variables estimated using Pearsons' correlation and chi-squared tests	• Families identified treating people respectfully and showing interpersonal sensitivity were central to providing supportive, enabling participatory care • However, the importance of treating people respectfully and sensitivity was not consistently rated across professional groups • Continuity of care and the provision of specific information to meet the family's needs if embedded into service and care delivery could enhance the delivery of family-centred practice in community settings
Sousa et al. (2013) Portugal	Survey of parental perspectives on negotiation of their child's care in hospital.	444 parents completed a 24 item questionnaire about being involvement in their child's care, and were recruited from 1 children's hospital Data were analysed suing a arrange of non-parametric tests including Pearsons' correlation, Mann Whitney U and Kruskal Wallis test	• Gaining information about their child's health condition was an overwhelming priority for parents; in general information needs were met • Parents reported that they wanted to participate in their child's care but did not want to disrupt nursing routines • In addition, parents were not always able to inform nurses if they did not wish to participate in their child's care • Most participants were able to contribute to decisions about their child's care • Being present during their child's hospital stay was perceived as important to their child's safety and wellbeing
Uhl et al. (2013) UuSA	Mixed methods study exploring parents experiences of family-centred care following their child's admission to hospital	9 parents participated from 1 children's hospital were recruited Data from focus groups were analysed using content analysis and inpatient hospital experience survey data were analysed using descriptive statistics	• A child' admission to hospital is a stressful event, associated with uncertainly, fear and lack of control in relation to meeting their child's needs; although implementing family-centred care was identified as challenging, involving parents can be a means of ameliorating their emotions, anxiety and stress • Characteristic valued in health professionals included treating parents with dignity, being courteous and actively listening to parents concerns • Information sharing was identified as central to involving parents in care

Author	**Study aim**	**Methods**	**Key findings**
Watt et al. (2013) Canada	Grounded theory study exploring Chinese and South Asian immigrant parents' experiences of care in paediatric oncology	50 Chinese and South Asian immigrant of children with a diagnosis of cancer participated and were recruited from 16 oncology hospital Data from interviews were analysed using constant comparative method of analysis	• Although parents reported positive experiences, components of family centred care such health professionals embracing family-centred care and not feeling part of their child's care team were identified • Parents reported the way health professional communicated health information, particularly when involving their child, was not always undertaken in a sensitive manner
Ygge et al. (2006) Sweden	Survey of hospital staff's perceptions of parental involvement in paediatric hospital care	207 participants including nurses and doctors from a range of specialities were recruited from 3 hospitals Data from a 26 item questionnaire, developed from focus groups, were analysed using exploratory factor analysis	• Perceptions of parent involvement in care differed across care specialties, with staff working in oncology units more likely to report routines and practices that facilitated involving parents in care • Time constraints and burden of work was perceived as a significant factor that impacted on daily working practice and an ability to response to parents need for information about their child's care • Some specialties relied on parents to provide daily care such as feeding, meeting their child's hygiene needs and occupying their child, and requested parents stay with their child overnight
Ygge & Arnetz, (2004) Sweden	Qualitative study that explored parental involvement in paediatric hospital care.	14 parents of a child with a long-term conditions participated and were recruited from 1 hospital Data from semi-interviews were analysed using constant comparative method of analysis	• Parents perceived that there was lack of support to assist them to care for their child and often there was lack of sharing of information • Interactions with professionals were valued as a means of discussing care and care options • Poor organisation of care delivery impacted on daily working practices and an ability to response to parent needs • Parents were vigilant to ensure care was delivered and be an advocate for their child

Antecedents of family-centred care and the partnership-in-care

In the context of this concept synthesis the antecedents, or the incidents leading to the concept synthesis (Finfgeld-Connett, 2007), related to the challenges of embedding family-centred care and partnership-in-care into every day practice. Figure 3 illustrates that the key antecedents of family-centred care and partnership-in-care identified through in our concept synthesis are: a theory-practice gap, unclear roles and boundaries, entrenched professional practices and attitudes towards working with families, and lack of organisational or managerial guidelines or policies specifically aimed at supporting the implementation of patient-centred care.

Figure 3: Antecedents relating to embedding the models into practice

Family-centred care	Partnership-in-care
• Gap exist between theory and practice (Coyne, 2011; Coyne et al. 2013b; Hughes, 2007; Murphy & Fealy, 2007) • Operationalising family-centred care is hindered by individual health professions attitudes towards, values and perception of and family-centred care (Ladak et al. 2013; Maccdonald et al. 2012) • Unclear roles and boundaries between parents and health professionals, entrenched professional practices with health professionals retaining role of decision maker, care prescriber and care giver (Bridgeman, 1999; Bruce et al. 2002; Coyne, 2013a; Hughes, 2007; Murphy & Fealy, 2007; Paliadelis, et al. 2005) • Inadequate nursing assessment and documentation relating to role negotiate; lack of knowledge and skills in relation to implementing family-centred care; operates without effective sharing of information, and collaboration or negotiation with families (Bruce et al. 2002; Coyne 2013a; Holm, et al. 2003; MacKay & Gregory, 2011) • Lack of organisational, managerial support, guidelines or policies hinders the implementation and consistency of embedding family centred care in practice of family-centred care (Coyne, 2011; Davies 2013, Coyne 2013b MacKay & Gregory, 2011; MacKean et al. 2005) • The design and organisation of the care environment can be facilitator or a barriers to embedding family to care into practice (Beck, 2009; Coyne et al. 2013b; Coyne, 2011; Koller et al. 2006; Bruce et al. 2002)	• Model outdated and does not reflect current practice' partnership professional rather than lay term (Coyne & Cowley, 2007; Fereday et al. 2010) • Shift from excluding parents to assuming participation in care has resulted in uncertainty about the role of parents and nurses; overreliance on parents as a resources; concerns about the quality of care provided in parents absence (Coyne & Cowley, 2007; Lam, et al. 2006 Ygge et al. 2006) • Established hierarchies, organisation culture and practices hinder involving parents in care (Coyne & Cowley 2007, Ygge et al. 2006) • Poor information sharing, lack of understanding lack of family context, not valuing parents knowledge and contribution to care hinder supporting parents in their role as care giver (Fereday et al. 2010; Ford, et al. 2011;Lam et al. 2006; Lee, 2007)

Key attributes of family-centred care and partnership-in-care

Furthermore, and as demonstrated in Figure 4, the key characteristics associated with family-centred care and partnership-in care drawn from the studies reviewed are summarized within three domains: (i) Valuing parents' knowledge and experiences (ii) supporting parents in their role as care giver, and (iii) Incorporating parents' expertise into clinical and psychosocial care.

Figure 4: Attributes associated with family-centred care and partnership in care

Domain	Attributes	
	Family-centred care	**Partnership in care models**
Valuing parents' knowledge and experiences	• Know the family and developing effective parent-professional relationship (Davies, 2012; Murphy & Fealy, 2007) • Collaborate and share decisions about child's care (Coyne, 2011; MacLean et al. 2007) • Effective communication skills (MacKean et al. 2005)	• Build trust, listen to parent concerns, value parents knowledge of their child (Fereday, et al. 2010; Ford, 2011) • Respecting and being sensitive to individual family's context (Raghavendra, et al. 2007)
Supporting parents in their role as care giver	• Provide opportunities for information sharing (Bruce, et al. 2002; Coyne, 2011; Coyne, 2013b; Holm, et al. 2003; Koller, 2006;) • Facilitate parents to involved in the child care; clarify and negotiate roles (Coyne, 2011; Holm, et al. 2003; Hughes, 2007) • Professionals have and share specialised knowledge to support family (Davies, 2012) • Design services round the child and family needs (Bruce, et al. 2002)	• Maintain contact and going support (Coyne & Cowley, 2007; Ford, 2011) • Mutual exchange of information about the child's specific health issues (Ford, 2011; Lam, et al. 2006; Lee, 2007)
Incorporating parents' expertise into clinical and psychosocial care	• Include and value parents contribution to the care team (Davies, 2012) • Clear roles and effective inter-disciplinary collaboration (Coyne, 2011; MacKean et al. 2005)	• Mutual agreement about roles (Coyne & Cowley, 2007) • Focus on problem-based communications by listening to the family, drawing on family expertise, responding to family concerns (Mäenpää et al. 2013)

Framework for involvement

Involving parents in the management of their child with a long-tem condition is likely to be influenced by the attitudes and actions of health professionals. Drawing on the antecedents and attributes associated with family-centred care and partnership in care identified in this concept synthesis; the parent-professional collaboration framework for involvement presented in Figure 5, depicts three domains and the associated processes and actions required to engage effectively and involve parents in their child's care. The first domain, valuing parents' knowledge and experiences reflects elements 1, 2, 3 and 9 of the framework developed by Shelton et al., that we outlined in the background to this paper. The second domain, supporting parents in their role as care giver reflects elements 4, 5 and 6 of Shelton et al's framework, and the third domain, Incorporating parents' expertise into clinical and psychosocial care reflects elements 7 and 8 of Shelton et al's framework. The practical framework of involvement derived from this concept synthesis aims to promote parent-professional collaboration for families of children with long-term conditions.

Figure 5: Parent-professional collaboration - a framework for involvement

Framework for involving parents in the care of a child with a long-term condition			
Domain	Valuing parents' knowledge and experiences	Supporting parents in their role as care giver	Incorporating parents' expertise into clinical and psychosocial care
Collaborative processes	Developing effective parent-professional relationships	Negotiating with parents the preferred level of support required from nurses	Ensuring transparency of participatory processes and documentation of parents contributions to care
Actions	• Elicit and respond to parents' concerns • Establishing rapport – develop a trusting relationship through on-going clear communication, learning about family context , active and listening and share parents experiences	• Mutual information exchange • Establish parents' contribution to the child's clinical care and desired level of involvement • Share decisions with parents and other professionals; collaborate when planning care planning	• Involving parents in diagnosis and treatment decisions • Facilitate parents to express their opinions about care decisions • Incorporate parents' knowledge of their child and care experiences within the clinical assessment, planning, delivery and evaluation of care

Discussion

Concept synthesis is designed to bring concepts and data from research together in a new and novel way to discover new insights (Finfgeld-Connett, 2007; Walker & Avant, 2011). Notwithstanding conceptual differences and lack of clarity in terminology, the attributes relating to family-centred care and partnership-in care were similar and included: valuing parents' expertise and knowledge about their child; forming trusting relationships with the child and family; facilitating the child and family to participate in care delivery through the process of negotiation, empowerment and shared goal setting ensuring effective information provision to enable the child and family to collaborate in care decisions. These attributes have been incorporated into the framework for involving parents in the care of a child with a long-term condition (Figure 5). Similarly, in an analysis of the major constructs underpinning family-centred care, Franck and Callery (2004) noted that child/family empowerment is enabled through respectful interactions; respect for families is demonstrated by providing support to them; and that family friendly facilities and shared decision-making are evidence of partnership working. However, Mikkelsen and Frederiksen (2011) suggest that the key attribute in family-centred care is the relationship between the family and professionals and that this 'relationship is characterized by a mutual dependency and shared responsibility for the child's care, which may have both positive and negative consequences and holds potential areas of conflict not fully explained by the attribute of partnership' (page 1152). Therefore they argue that partnership may be an irrelevant concept, instead the focus should be on the family-professional relationship and efforts should be directed towards explicating the issues around shared responsibility, and mutual dependency. Clearly, the lack of agreement about the meaning of family-centred care and partnership-in-care and the fact that they are interrelated creates difficulty for nurses and may account for nurses' concerns about how best to involve families in care. We offer this synthesis as a practical framework that has a central theme which is the involvement of families in the care of children with long-term conditions. It identifies the key domains (what is of importance), making explicit the processes (how it should happen) and then identifying the actions to support the process

Despite the concepts of family-centred care and partnership-in care being well established within the health literature and policy directives, this concept synthesis suggests implementation of these concepts into everyday practice remains problematic. The reasons why these concepts remain somewhat aspirational and challenging for health professional to implement as identified in Figure 3 include: poor conceptualisation of the concepts; lack of understanding and commitment to implementing these concepts; and anxieties about role adjustments. These exact same challenges have been identified by other authors who have undertaken reviews of family-centred care (Shields et al, 2012).

For mothers and fathers of children with long-term conditions, family life often focuses on the demands of managing the child's condition (Swallow, Macfadyen, Santacroce & Lambert, 2012; Knafl, Deatrick, Gallo, Grey & Dixon, 2013); Swallow, Nightingale, Williams, Lambert, Webb et al., 2013), and the evolving role of parents to one of care provider (Ward, Glass & Ford, 2014). Through experience, parents become responsive to their child's needs and can provide highly individualised care (Bailing & McCubbin, 2001; Kirk, Glendinning & Callery, 2005; Ward, Glass & Ford, 2014). Consequently, parents develop considerable expertise in managing their child's long-term condition (Bailing & McCubbin, 2001: Dickinson et al., 2006: Nuutila & Salanterä, 2006). The process of developing this expertise has been described as blending knowledge and skill acquisition with experiential knowledge in order to adapt to changes in the child's condition (Bailing & McCubbin, 2001; Cashin, Small & Solberg, 2008; Smith, et al., 2013b). Moving from a novice to an expert is not solely achieved by gaining experience and knowledge but is a process of change and involves developing the skills to critically analyse new situations and effectively problem-solve (Dryfus & Dryfus, 1996).

In relation to developing the expertise to care for their child with a long-term condition, it has been suggested that mothers, through realising they had intimate and detailed knowledge of their child and their condition began to trust their own judgements when managing their child's condition; this resulted in the mothers becoming highly attuned to changes in their child (Gibson, 1999). Mothers developed the necessary expertise to meet their child's needs and if necessary challenging health professionals' decisions. Gibsons' (1999) seminal work linked the notion of expert mother to the process of empowerment and the concept of critical reflection, and has informed the ongoing debate on parental expertise in the parent-health care professional partnership (for example Dickinson, et al., 2006; Miller, et al. 2009; Nightingale, Sinha & Swallow, 2014).   Understanding the nature of expert parents in terms of the attributes that constitute becoming an expert, and the ways health professionals engage with and incorporate expert parents' opinions into care decisions when working with children with long-term conditions, may facilitate better parent-professional engagement and collaboration. Evidence suggests the quality of parent-professional relationships is variable and the process of developing effective relationships with health professionals can be stressful for parents (Dickinson et al. 2006; Miller, Condin, McKellin, Shaw, Klassen & Sheps, 2009; Nuutila & Salanterä, 2006).

Parents managing childhood long-term conditions want to work in partnership with health professions; however ensuring their detailed knowledge of the child's care and response to treatments is heard can result in tensions when engaging with health professionals (Smith et al., 2013c). Entrenched health professional practices such as retaining the role of decision maker, care prescriber and care giver were identified as core antecedents and barriers to implementing family centred care in this concept synthesis (Figure 3). Yet, international health policy relating to the concept of the 'expert patient' (or parents in the case of young children) espouses the need to support patients to self manage their condition, where perceived self-efficacy improves an individuals' confidence to manage their condition effectively and make informed health decisions (Bury, Newbould & Taylor, 2005: Foster, Taylor, Eldridge, Ramsay, & Griffiths, 2007; Lorig & Holman, 2003).

Developing effective parent-professional relationships has been described as an evolving process that is initially professionally dominated but through time moves to one of collaboration (Swallow et al, 2013). Parents and professionals may find their relationships are challenged as the balance of power shifts from a professionally dominated to a collaborative paradigm, although some may accomplish common ground during the practice of shared care (Smith et al, 2013c; Swallow et al, 2013). Involvement meant that nurses listened to and valued parents' experiences and involving them in diagnosis and treatment decisions was enabled by the actions and attitudes of health professionals (Hummelinck & Pollock, 2006). Effective involvement enables parents to express their opinions using active listening and responding to parents' concerns, building rapport with parents, valuing parents' knowledge and experiences with effective information exchange and mutual care planning. The framework for involving parents in the care of a child with a long-term condition, presented in Figure 5, advocates ways to promote parent-professional collaboration for families of children with long-term conditions.

Limitations of concept synthesis include the fact that although the process is useful to describe concepts, frameworks or theories developed from the process require subsequent testing and verification. The framework we propose, therefore, requires evaluating by nurses working with children and parents, and consideration of its applicability for working with children or young people who are beginning to share responsibility for the management of their condition with parents, and health professionals. One of the limitations of this synthesis is that the literature included is not exhaustive. Although an even wider search is likely to have identified additional studies for inclusion, the similarity of antecedents and attributes suggest the resulting framework has potential value in practice.

Conclusion

Despite the concepts of family-centred care and partnership-in care being well established within the health literature and policy directives, this concept synthesis suggests that implementation of these concepts into everyday practice remains problematic. The resulting framework for involving parents in the care of a child with a long-term condition is offered as a foundation for the work of professionals aiming to support parents in health care contexts.

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