

FAMILY-CENTRED CARE IN CHILDREN'S NURSING –
PERSPECTIVES, CHALLENGES AND THE CHILD'S VOICE:
A CRITICAL LITERATURE REVIEW

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Abstract

This literature review investigates a possible theory-practice gap within Family-Centred Care in children's nursing. The investigation into this theory-practice gap was conducted by critically examining primary research that presents perspectives of those involved in Family-Centred Care. Nursing, family and children perspectives were examined to reveal a number of perceived challenges of Family-Centred Care in children's nursing. However children's perspectives revealed that children may not experience the same challenges, suggesting that children's views and the child's voice may help to resolve the theory-practice gap. The rights of the child support the idea that the child's voice is fundamental in children's nursing, however it was revealed that the child's voice may not be acknowledged as it should. This may be due to poor understanding of the multidimensional 'voice'. Role identification and decision-making are examples of why the child's voice should be fundamental in children's nursing and this could be improved with changes in nursing education. Children's nursing may need to re-direct its focus from Family-Centred Care to a more child-centred model. Child-Centred Care is an area for further investigation to enhance the findings of this literature review.

FCC IN CHILDREN'S NURSING

For my Mum, who I am unable to share this with. You inspire me every day, I hope I am making
you proud.

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Table of Contents

Abstract ii

Dedication iii

Acknowledgements iv

Table of Contents..... v

List of Tables vi

Chapter One..... 1

 Personal Interest 1

 Purpose of this Literature Review..... 2

 Method..... 2

 Search Results..... 3

Chapter Two 5

 Background..... 5

 Evolution of Children's Health Care and the Development of FCC 7

Chapter Three..... 15

 Nursing Perspectives 15

 Family Perspectives 26

Chapter Four 33

 Children's Perspectives..... 33

Chapter Five 39

 The Child's Voice..... 39

 Conclusion..... 47

References 49

List of Tables

Table 1. Organisation of Primary Research	10
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Chapter One

This literature review will examine Family-Centred Care (FCC) in children's nursing in order to explore a possible theory-practice gap. A range of literature will be reviewed in order to discuss the foundations of FCC in children's nursing, its application, evolution and challenges of implementation in practice. This chapter begins with an explanation of how personal interests developed into a topic for this literature review. Following this, the purpose of the review will be outlined along with details of the method used for searching the literature. The second chapter will provide a background on FCC and explain how FCC has developed alongside children's nursing. This will include identification of important theoretical concepts of FCC and partnership, and the existence of a theory-practice gap. The third chapter will present a critical examination of primary research that investigates nursing and family perspectives on FCC in children's nursing and the fourth chapter will do the same for children's perspectives. The findings of this examination will be considered in the fifth chapter, in which challenges that lead to the theory-practice gap will be addressed and possible ways forward for FCC discussed.

Personal Interest

My interest in FCC grew from curiosity of children's nursing. As a student, my experience in this field of nursing currently reaches only as far as the literature. However, from this alone I discovered that the skill-base and knowledge involved in nursing a child and family is different to that of adult nursing on many levels. I already had an interest in working in a negotiated partnership with patients, from my experiences in adult nursing and was interested in how this role may change, in the context of children's nursing.

FCC IN CHILDREN'S NURSING

I focused my initial literature search on the negotiated partnership with children, but with further research I identified that the inclusion of the family when caring for a child is a large factor in this partnership. This refined my research further, until I was introduced to the concept of Family-Centred Care. With only a glance at work on this concept, I established that it has high relevance and importance in children's nursing. I also established that the application of FCC in this area carries with it some challenges, one in particular being a theory-practice gap and I was immediately drawn to the idea of investigating this. This topic also resonates with me on a personal level as I have a family-member whose son is currently receiving hospital-level care. Talking with this family member assured me that the concept of FCC is a very relevant issue in nursing; as the family member had both positive and negative things to say about it based on personal experience.

Purpose of this Literature Review

This literature review aims to examine current published research on FCC and partnership models of care in children's nursing, in order to investigate a theory-practice gap. The findings will be discussed in order to determine possible solutions to challenges in the application of FCC to practice.

Method

A literature search was performed in order to identify current published research on FCC in nursing. The search was performed on the following databases and search engines: CINAHL, MEDLINE and Google Scholar. The studies included in the critical examination of this review are all within the 2005-2015 period, as these are the most recent and relevant. Search terms were

FCC IN CHILDREN'S NURSING

used as key words as much as possible to ensure FCC was examined in a range of different contexts. Key search terms were: 'family-centred/centered care', 'family-centred/centered nursing', 'participation', 'partnership', 'paediatric/pediatric nursing', 'child nursing', 'children's nursing', 'family', 'nurse perspectives', 'family/parent perspectives', 'child's voice', 'child/children perspectives'. Literature reviews were filed separately from primary research in preparation for both a descriptive and critical review. Literature was excluded if it was not written in English, or did not include at least two of the following key words: 'Family-centred care'; 'partnership'; 'participation'; and 'perspectives'. In addition to this, primary research was excluded if it did not state a purpose to examine perspectives of nurses, families or children. An additional search was conducted using the key words 'child's voice', 'children's nursing' and 'child-centred care'.

Search Results

Seven pieces of primary research were selected for critical examination and all were published between 2007 and 2015. Of these, three studies were utilised to examine nursing perspectives only, one was utilised to examine family perspectives only, one was utilised to examine children's perspectives only, one was utilised to examine nursing and family perspectives and one was utilised to examine all three perspectives (Table 1).

FCC IN CHILDREN'S NURSING

Table 1

Literature Included in Review

Perspectives	Primary Research
Nursing	Lee (2007) Hughes (2007) Coyne (2008a) Coyne et al. (2011) Coyne (2015)
Family	Hughes (2007) McDowell et al. (2015) Coyne (2015)
Children	Pritchard Kennedy (2012) Coyne (2015)

Chapter Two

Background

This chapter will explain the concept of Family-Centred Care (FCC) in children's nursing and provide an explanation of its history and evolution. FCC is a philosophy of care used in children's nursing and utilised in many health care settings around the world (Harrison, 2010). To understand the concept of FCC, it is necessary to explore how it is defined in the literature.

Shields, Pratt and Hunter (2006, p.1318) suggest that FCC is "a way of caring for children and their families within the health services, which ensures that care is planned around the whole family, not just the individual child or person, and in which all family members are recognised as care recipients". Evans (1994, p. 477) suggests that the concept of FCC is best defined as "care-by-parents"; an interesting suggestion, as it can be argued that family is not defined as just "parents". Casey (1988) (cited in Lee, 1998, p. 205) suggests that family means not only parents, but any others who significantly influence the continuing care of the child'. Stower's (1992, p. 68) definition of FCC refers to FCC in a specific environment; "partnership caring; focusing the child's care around the child and their family and including as much normal homelike activity as is possible in the hospital". Smith, Coleman and Bradshaw (2009, p. 27) perhaps encompass all of these concepts and propose a definition, which could be argued as a leading one for FCC research and implementation; "The professional support of the child and family through a process of involvement, participation and partnership underpinned by empowerment and negotiation". Although a wide range of definitions exist, academics and health professionals acknowledge that FCC is governed by a number of principles or key

FCC IN CHILDREN'S NURSING

elements; these principles are visible in FCC practice today (Smith, Coleman & Bradshaw, 2009).

A popular list of key principles was generated by Shelton and Stepanek (1994) which, when summarised includes; acknowledgement of the family as a constant in the child's life; facilitating of family-professional collaboration at all levels of hospital, home and community care; exchange of complete and unbiased information between families and professionals; honoring of cultural diversity; recognising and respecting different ways of coping; encouraging family-to-family support networking; ensuring support systems are accessible, flexible and comprehensive; and appreciating families as families and children as children. These elements are built on a foundation of communication, which holds them all together, and crafted with the intention that each succeeding element strengthens the one before it (Shelton & Stepanek, 1994).

Other sets of principles exist in the literature. More recently, Kuo et al. (2012) summarised a list of general FCC principles; information sharing, respect and honouring differences, partnership and collaboration, negotiation and care in context of family and community. There are similarities between these principles and those of Shelton and Stepanek. For instance, the category of respect and honoring differences includes cultural diversity and differences in coping, both of which are included in Shelton and Stepanek's key elements of FCC (Kuo et al., 2012, Shelton and Stepanek, 1994). Another similarity is the acknowledgment of flexibility of support services, procedures and practices (Kuo et al., 2012, Shelton and Stepanek, 1994).

However, the principles of Shelton and Stepanek (1994) have been critiqued for only focusing on the attributes of FCC and not giving insight into implementation of FCC in practice (Hutchfield, 1999). Kuo et al. (2012) could be critiqued for the same reason, as well as not

FCC IN CHILDREN'S NURSING

acknowledging the evolution of FCC. Smith, Coleman and Bradshaw (2009) suggest that the existence of various principles signifies both holistic and functional views of FCC. While Shelton and Stepanek (1994) and Kuo et al. (2012) may represent the holistic view, Nethercott (as cited in Hutchfield, 1999) denotes a more functional one. Nethercott (Hutchfield, (1999) presents a list of components of FCC that acknowledge the use of FCC in practice. This list of principles focuses on supporting family members' participation and partnership, and is clearly more appropriate for the practical setting. These principles include, the family must be viewed in its context; the roles of individual family members must be evaluated; families should be involved in the technical aspects of care; usual child care practices promoted in hospital, unless detrimental to the child; the support given to families should continue after discharge (Hutchfield, 1999, p.1180). Although Nethercott's (Hutchfield, 1999) list of principles appears to be more representative of how FCC should be practiced, it may be too task-focused and exclusive of wider aspects. It is possible that a list constructed from both the holistic and functional principles could be a more ideal balance of attributes and application.

Evolution of Children's Health Care and the Development of FCC

The United Kingdom is the source of much of the recent and relevant literature on FCC in child health; this is also true for historical literature. FCC has been evolving and developing in children's health care since the 1950's and Shields (2010) suggests that until this time, the concept of Family-Centered Care and the principles it represents were unheeded amongst health professionals, including nurses. Before this time, children were admitted to hospital and parents were allowed to visit for, at best, half an hour per week (Jolley & Shields, 2009). Carter, Bray, Dickinson, Edwards and Ford (2014) suggests that this was because the strong, emotional

FCC IN CHILDREN'S NURSING

response of children to these visits was viewed as harmful and infection control was of high priority. However, Jolley and Shields (2009) propose that it was due to ignorance of clinicians to the developmental, social and psychological needs of children, which was rife during this time; children viewed hospital staff as “non-human” and nurses as “uncaring” (Jolley & Shields, 2009, p. 165). Bruce and Ritchie (1997) propose that recognition of the pivotal role of family in the child's life was critical in the evolution in children's health care and the development of FCC.

Bowlby, Robertson and the Platt Report. The mid-twentieth century saw a period of social change and a turning point in attitudes towards care of children in hospital in the UK. Jolley and Shields (2009) suggest that a catalyst for this change was World War II, as it brought with it much suffering and grief from separation, resulting in increased concern for the psychology of both adults and children. Work by child psychologist John Bowlby, social worker James Robertson and the release of the Platt Report in 1959 in Britain, steered research on the psychological effects of parental separation for the ill child. Bowlby published about separation anxiety, grief and the attachment theory (Alsop-Shields & Mohay, 2001). Although he was criticised for making broad assumptions with limited data, Bowlby crafted new thinking and generated much research regarding the potential damage separation can cause a child (Alsop-Shields & Mohay, 2001). Robertson formed a theory of phases of child responses to a stay in hospital without the mother; these phases were protest, despair and denial/detachment (Alsop-Shields & Mohay, 2001). Robertson also presented both his and Bowlby's research to a range of health professions in the form of films (Alsop-Shields & Mohay, 2001). Although Bowlby and Robertson were not nurses, their work is believed to have reached a wide range of nursing circles

FCC IN CHILDREN'S NURSING

at the time and informed a number of changes in children's nursing (Alsop-Shields & Mohay, 2001).

Bowlby's work was utilised and disseminated all around the world by James Robertson, who made seminal films of the effects of parental separation during hospital admission (Jolley & Shields, 2009). However, Bowlby and Robertson's research directions eventually began to move away from each other; as Bowlby continued as a theoretician. Robertson, with help from his wife, continued to make films that had a significant impact on health professionals (Alsop-Shields & Mohay, 2001). Despite their parting of ways, Bowlby and Robertson etched the beginnings of FCC into child health and they influenced significant publications in health care.

One of these publications was The Ministry of Health Report, *The Welfare of Children in Hospital*, better known as The Platt Report (1959), it offers a list of recommendations for a more humanitarian approach to children's nursing (Carter et al., 2014; Darbyshire, 1993). The report was a catalyst for a union of opinions in the British health system, as well as other countries (Davies, 2010). It represented important changes in society and hospital care systems and altered the attitudes of health professions towards the parents of sick children (Davies, 2010). However, The Platt Report was slow to be implemented in all areas of child health (Darbyshire, 1993) and it could be argued that its recommendations have not yet been fully addressed today (Davies, 2010). Despite this, many of the report's recommendations have been implemented and provide the foundations of the evidence bases of many child health nurses (Davies, 2010). The Platt Report and the work of Bowlby and Robertson were evidently fundamental to the development of child health and therefore facilitated the growth of FCC in children's nursing; in fact their work has influenced many of the models of FCC seen today (Alsop-Shields & Mohay, 2001).

FCC IN CHILDREN'S NURSING

Advocacy Groups. The work of Bowlby and Robertson and their influence on the Platt Report are major foundations of many groups advocating for child health services; many of these groups supported the development of FCC and became important FCC advocacy groups (Alsop-Shields & Mohay, 2001). In 1961, a group called Mother Care of Children in Hospital was founded in Britain to ensure the enactment of the recommendations of the Platt Report (Jolley & Shields, 2009); this became the National Association for the Welfare of Children in Hospital (NAWCH), which is now Action for Sick Children (Alsop-Shields & Mohay, 2001).

This group was the catalyst for other advocacy groups. In the USA, The Association for the Care of Children in Hospital (ACCH) was created and the Association for the Welfare of Children in Hospital (AWCH) formed in Australia in 1973 (Alsop-Shields & Mohay, 2001). Alsop-Shields and Mohay (2001) suggest that later work from Robertson and his wife encouraged these advocacy groups to form to ensure maintenance of good paediatric practices. This was the inspiration for the establishment of the Institute of Patient- and Family-Centred Care (IPFCC) in America in 1992, which became heavily involved in advancing understanding and practice of FCC; the IPFCC continues to have a major influence on FCC policy and development in the US and prioritises many of the FCC principles proposed in the literature (Institution for Patient- and Family-Centred Care [IPFCC] 2010). Although these groups advocate for FCC practice, they are confined to single countries and are not necessarily specific to nursing.

Casey's Framework. One of the models of FCC, influenced by the work of Bowlby and Robertson, is Partnership-in-care; this was developed by New Zealand nurse Anne Casey, who was working in the UK at the time (Jolley & Shields, 2009). The model started to emerge in the

FCC IN CHILDREN'S NURSING

early 1990's and involved two main principles; nursing care for a child in hospital can be given by the child or parents, with support and education from the nurse; and family or parental care can be given by the nurse if the family is absent or unable or unwilling to provide the care they normally provide (Jolley & Sheilds, 2009, p.168).

Casey (cited in Lee, 1998) emphasised the importance of viewing the family as a whole, and encouraged active participation in both normal family or parental cares and nursing cares. Lee (1998) suggests that Casey's main aim was to create equilibrium between the child, family and nurses, using partnership as a focus. Casey provides a definition for family, "usually considered as a group which carries out certain social and biological functions...taken to mean parents and others who significantly influence the continuing care of the child" (Lee, 1998, p.205). Farrell (1992) explains that Casey's model involves five concepts: the child, health, environment, family and the nurse and is a flexible way to design care to suit the needs of a sick child. The model takes into account the importance of roles and responsibilities and encourages active participation and partnership between different roles (Farrell, 1992).

It would be fair to argue that Casey's Partnership-in-Care model is a fundamentally relevant to FCC and studies investigating partnership in practice will be explored in the next chapter. However, as the next chapter will identify, application of the model to practice is not a simple feat. It is important to identify the challenges presented in the application of FCC to practice in the child health setting.

Darbyshire's Research. Darbyshire's (1993) research, about parents and nurses in paediatric nursing, was key in that it led to acknowledgment of the challenges associated with FCC implementation in children's nursing. Darbyshire (1995) points out that there is a danger of

FCC IN CHILDREN'S NURSING

prevailing a positive and uncritical view of FCC because it has evolved to improve children's health care from what it once was. However, the application of FCC is not unproblematic and Darbyshire (1993) suggests that the implementation of FCC is not as the literature would suggest. Some problems that Darbyshire (1995) identified included; nurses' views of "families" are not the reality, but socialised ideals; nurses struggle with determining the roles of different family members; the needs of the parent, in specific circumstances, were not being identified; and parents having to exist in a different environment, now performing everyday tasks in "public". Darbyshire (1995) concluded that children exist in a "web of relationships" and, despite the positive attributes of FCC, its application to practice is not as simple as some literature may suggest.

FCC Today. Coyne et al. (2011) states that, more recently, the concept of FCC is practiced through a range of different theories and perspectives; from parent participation in care, to partnership-in-care, to care by the family as a whole. Despite this range of views, Jolley and Shields (2009) suggest that the theoretical foundations of FCC are widely and commonly acknowledged around the world. Many relevant theories are demonstrated in practice and Bowlby and Robertson's work continues to form the theoretical base of FCC understanding (Alsop-Shields & Mohay, 2001). Most child health professionals believe that FCC has become the best way to deliver care to children in hospitals (Jolley & Shields, 2009). According to Carter, Bray, Dickinson and Edwards (2014), FCC is the most common theoretical method reinforcing child nursing in Western countries, including New Zealand, the United States, Canada and the United Kingdom.

FCC IN CHILDREN'S NURSING

However, despite the apparent popularity of FCC, it is clear from the existing literature that its implementation in practice appears to present challenges for nurses (Coyne et al, 2011; Shields, 2010; Shields, 2005; Franck & Callery, 2004; Shields, Pratt & Hunter, 2005; Bruce & Ritchie, 1997). This results in inconsistent application of FCC in the clinical setting, which is supported by a dearth of evidence relating FCC to improved child health outcomes (Foster, Whitehead & Maybee, 2010). Ultimately, Shields (2010) suggests that the FCC model is merely an ideal, given lip service in documents and policies, but lacking in evidence; this echoes earlier criticism by Darbyshire (1995).

Franck and Callery (2004) identified the “theory-practice gap”, arguing that although there is a vast collection of reliable literature on FCC, it is not translated into consistent and effective practice in the clinical setting. In addition, there is a distinct absence of reliable evidence of the use of FCC in children’s nursing. This argument is supported in literature by academics, including nurses, who argue that the reasons for this “theory-practice gap” should be examined (Foster et al, 2010; Franck & Callery, 2004; Coyne et al, 2011; Bruce & Ritchie, 1997; Kuo et al, 2012; Shields et al., 2006). One way to do this, is to critically examine literature that assesses the perspectives of those involved in FCC in children’s nursing

Chapter Three

This chapter will focus on the perspectives of nurses and families on FCC in children's nursing. A large amount of literature refers to these different perspectives in an attempt to explore the use of FCC in children's nursing. With this in mind, examining the nursing perspective of FCC in children's nursing, and the theory it is built on, is an obvious place to start when probing the theory-practice gap. As described in the previous chapter, both Casey (cited in Lee, 1998) and Darbyshire (1995) discussed partnership and participation as fundamental aspects of children's nursing and Lee (2007) argues these aspects are part of the FCC spectrum. This spectrum is described by Smith and Coleman (2009) as a practice continuum that can be practiced at different levels, depending on parent needs and nurses' abilities to facilitate partnership. Shields, Pratt and Hunter (2006) suggest that partnership between family and health professionals is a primary principle of FCC. Considering this, studies examining perspectives of partnership and participation by nurses and families will be included in this chapter.

Nursing Perspectives

Lee (2007). Partnership with families in children's nursing is explored by Lee (2007), who studied a small sample of nurses (n=10) in an inner city trust in the UK. The study was conducted using semi-structured interviews and Lee (2007) justifies the use of these by explaining the benefit of interviewing based on topics or schedules, as opposed to pre-defined, scripted questions. This is supported by Barriball and While (1994, p.330) who state that semi-structured interviews are 'well suited to the exploration of perceptions and opinions...and enable probing of more information and clarification of answers'. Lee (2007) used convenience

FCC IN CHILDREN'S NURSING

sampling to enlist participants, all of whom were nurses with the same level of experience (NHS clinical grading, or equivalent, of 'F' or above, ie; Senior staff nurses) from one hospital trust. This may not be representative of all those involved in FCC in children's nursing, excluding nurses of other experience levels in many different settings.

The interviews yielded data that revealed several themes. One of these themes was attitudes. Lee (2007) reported that the participants implied that if nurses had positive attitudes, then partnership in care would work; they also related attitude to the nurse's experience, suggesting the more experienced a nurse is, the more positive attitude they will have towards the family. Most nurses commented on the failure of partnership in care due to negative attitudes in the multi-disciplinary team, as perceived by the participating nurses; their views were that the team's attitude stretched only as far as informing the family, not discussing options with them further. This is not in keeping with the importance placed on communication as a foundation for the principles of FCC (Shelton & Stepanek, 1994). However, another perspective amongst Lee's (2007) themes was that communication is essential between the nurse and family in partnerships. Another perspective was that a successful partnership was considered to result in improved well-being for the child, family and nurse. In addition, it was identified that partnerships fail because parents have a lack of understanding. The latter perspective suggests challenges with role identification. Casey's partnership model (cited in Farrel, 1992) emphasises the importance of roles and responsibilities in a partnership, which would suggest that without role identification, the partnership will fail.

Nurses in this study recognised the improved well-being for a child, as a result of having their family present with them. This illustrates one of the key principles and elements of FCC

FCC IN CHILDREN'S NURSING

identified in the previous chapter, that the family is constant in the child's life (Shelton & Stepanek, 1994). This view is shared by nurses in other studies, including Hughes (2007).

Hughes (2007). Hughes (2007) examined the attitudes of nurses towards FCC in children's nursing. This study utilised a questionnaire to assess the attitudes of nurses and parents towards the use of a this model of care in a children's unit in a general hospital in Ireland. The perspectives of the participating parents in this study will be examined later in the chapter.

All of the participating nurses (n=28) recognised that the presence of parents in the hospital is beneficial for both parents and the child, but a large group (n=12) also acknowledged an underestimation of parents' abilities to learn to care for their child. At the same time, over half of the nurses (n=16) felt they were good at teaching parents new skills. Some of the nurses (n=11) also thought that parents did not understand their roles in the partnership, that they did not know 'what was expected of them' (Hughes, 2007, p. 2345). This issue of role identification suggests that Casey's (1988) theory of partnership (cited in Lee, 1998) is not demonstrated here.

The data collection method used in this study does not lend itself to elaboration or deeper understanding of the initial results; Springwood and King (2001) highlight that questionnaires can be superficial. This questionnaire contained closed-ended questions to generate fixed responses to statements, however, to ensure validity, a pilot study was conducted in advance and the questionnaire was altered in accordance (Hughes, 2007). The following study demonstrates a different methodology to the one Hughes (2007) used.

FCC IN CHILDREN'S NURSING

Coyne (2008a). Coyne (2008a) carried out a grounded theory method study to investigate perspectives on parental participation in child health care. Coyne and Cowley (2006) conducted a study prior to Coyne's (2008a) research, in order to assess the use of the ground theory method to research parent participation in children's nursing. Coyne and Cowley (2006) suggest that this method allows the development of theory, to explain social processes (including perspectives) of the area being investigated. Coyne (2008a) aimed to investigate parent participation in the hospitalised child's care from the perspectives of children, parents and nurses. The nursing perspectives (n=12) are of importance and Coyne (2008a) presents findings in both positive and negative trajectories.

Trajectory one describes the nursing actions that the nurses related to positive outcomes of parental participation. These actions included taking a step back, as well as allowing the parents to do so if they felt uncomfortable and giving support and guidance when needed. This illustrates key principles of FCC, such as accepting different ways of coping and ensuring support systems are accessible (Shelton & Stepanek, 1994). The outcomes that nurses perceived as positive included; parents learn what is expected of them, parents conform to the social order and participate in the approved way and parents get rewarded with popularity and gaining extra attention. It should not be ignored that these nursing perspectives, revealed over a decade after Darbyshire's (1995) research emerged, show a lack of awareness of the challenges in FCC application in children's nursing. Darbyshire (1995) suggests that nurses have socialised ideals when it comes to the family. As a result, the nurses struggle with determining the roles of the family in caring for their child. This is evident in the nursing perceptions of positive participation outcomes in this study, which illustrate the challenges in identifying the needs of parents and family in specific circumstances (Darbyshire, 1995).

FCC IN CHILDREN'S NURSING

Trajectory two describes the nursing actions believed to have resulted in negative outcomes of parental participation. These include identifying and labelling non-compliant parents and managing parents with different strategies; the inclusionary strategy of attempting to persuade, influence or coerce, or exclusionary strategies, where nurses minimise direct contact between themselves and parents. Casey (cited in Lee, 1998) emphasised the importance of equilibrium in partnership, a balance between all those involved, which is not demonstrated in either of the positive or negative outcomes. The outcomes perceived as negative included parents do not learn what is expected of them, parents do not conform to the norms of the ward, a widening communication gap between parents, and nurses and participation not fully established in a meaningful way. The issue of role identification, identified in Lee's (2007) study is repeated here and these outcomes reflect the unrealistic and socialised nursing view of parents and families that Darbyshire (1995) identified over a decade ago. However some of the identified negative outcomes, such as a widening communication gap and participation not being meaningfully established, would suggest that nurses are partially aware of what makes a successful partnership in children's nursing.

The sample size of this study (n=12) could be considered small as participants were only based in two hospitals in the UK, however Kneale and Santy (1999) suggest that sample size is of less importance when the purpose of the research is to investigate a broad topic, rather than individual relationships. McCann and Clark (2004) suggest that when using the grounded theory method, the researcher is assumed to be both subjective and objective, but must be clear of how this will be attempted. Coyne (2008a) stated that credibility for the study is established through acknowledgement of personal and professional knowledge; this involves recording all actions, interactions and subjective states to avoid data distortion.

FCC IN CHILDREN'S NURSING

Coyne (2008a) identified that further research was needed to enhance the results of this study and contribute to knowledge in this area. Another of Coyne's studies (Coyne; O'Neill, Murphy; Costello & O'Shea, 2011), does this by building on the findings of nursing perspectives and identifying the implications for research and practice.

Coyne, O'Neill, Murphy, Costello & O'Shea (2011). This study (Coyne, O'Neill, Murphy, Costello & O'Shea, 2011) that also investigated the perspectives of nurses, identifies their practices and perceptions of FCC in children's nursing. The participants of the study were all nurses (n=250), working in seven of the 19 children's units across Ireland. Coyne et al. (2011) utilised a survey design, utilising The Family-Centred Care Questionnaire-Revised (FCCQ-R), developed by Bruce and Ritchie (1997). The validity of this tool is not well supported in the literature and Coyne et al. (2011) does not discuss how validity was ensured in this study. Coyne et al. (2011) reports findings from two open-ended questions included in the questionnaire: 'In your own words identify what FCC care means to you?' and 'What is needed to enhance FCC in clinical practice?' (Coyne et al., 2011, p. 2563).

The results of the study identify two main themes; "components of FCC" and "factors which enhance FCC". Each of these themes included several categories, which Coyne et al. (2011) argues present essential elements of FCC from the nursing perspective. Information sharing is a familiar element identified in the findings; nurses reported that this and decision-making were essential elements of FCC and the importance of a holistic approach to FCC is emphasised. Information sharing is one of the key principles presented by Shelton and Stepanek (1994) who suggest that the exchange of complete and unbiased information between families and professionals is an important element of FCC. One statement included in the results of this

FCC IN CHILDREN'S NURSING

study is “FCC is the care of the child and parents, siblings and other relevant family members e.g. grandparents, aunts, uncles. This care incorporates the medical, physical, social, psychological, spiritual and financial needs of the child and family during a hospital admission.” (Coyne et al., 2011, p. 2566). This is reflective of Casey’s definition of family (Lee, 1998) who emphasises viewing the family as a whole. It also acknowledges that the family is constant in the child’s life (Shelton and Stepanek, 1994), which Coyne et al. (2011) reports is identified in this study. Nurses also recognised that support and supervision of families are the main aspects of a nurse’s role in FCC. Family participation, partnership, negotiation and delivery of high quality care were all viewed as main components of FCC by nurses, which is reflective of the various definitions, principles and theories identified in chapter two (Shelton & Stepanek, 1994; Smith, Coleman & Bradshaw, 2009; Shields, Pratt & Hunter, 2006; Stower, 1992; Kuo et al., 2012). The nurses also advocated for the need for a multi-disciplinary approach to FCC, Coyne reported that the nurses considered a collaborative approach as vital in order to meet the needs of the child and their family, not just the needs of the nurses. This relates back to the study by Lee (2007), who reported that some nurses held multi-disciplinary teams responsible for failed partnership in care.

The multi-disciplinary approach is a central subject of the second theme, “factors which enhance FCC”, which focuses largely on the need for managerial and organisational supports for successful FCC in children’s nursing. Coyne et al. (2011) reports that the environment is viewed by nurses as in need of improvement to become more child and family friendly. It was also viewed that hospital facilities should cater more for FCC by way of more comfortable waiting rooms, improved orientation facilities and specific rooms such as parent and family rooms, breastfeeding rooms and teaching rooms. Psychosocial and financial supports were also identified as factors that enhance FCC and nurses recommended more support services be

FCC IN CHILDREN'S NURSING

provided, such as counselling and family liaison nurses, and financial supports such as reduction in car parking costs and meal expenses. Information sharing was mentioned as part of a need for improved communication and recommendations were made with reference to this, such as workshops for families and more written information on wards for families to read. Nurses also highlighted the need for appropriate staffing levels, as staffing shortages contributed majorly to the frustration they felt over not delivering beneficial FCC. Nurses also highlighted possible issues of their own doing, including general abuse of negotiation and staff relying too much on parents (Coyne et al., 2011).

The aim of this study was to report nurses' perceptions and practices of FCC (Coyne et al., 2011). This aim suggests there is a difference between perceptions and practices and nurses may view FCC differently to their experiences of it in practice. This could be helpful in investigating the theory-practice gap, however the open-ended questions do not allow for differentiation between perceptions and practice in the data. It should also be noted that the questionnaire only had a 33% response rate and this may introduce bias and unreliability (Smeeth & Fletcher, 2002). Despite this, Coyne et al. (2011) gives insight into how nurses perceive FCC practice in child health and a similar and a more recent study by Coyne is the next to be discussed in this chapter.

Coyne (2015). This study by Coyne (2015) utilised in-depth interviews to explore parents, children and nurses' perspectives and experiences of FCC and gain an understanding of roles and relationships and how these are negotiated. This is very relevant as Casey's model of partnership-in-care takes into account roles and responsibilities (Farrel, 1992). The participants in this study were from two different children's hospitals and one children's unit in a large

FCC IN CHILDREN'S NURSING

general hospital in Ireland (Coyne, 2015). Coyne identifies four main themes; expectations, relying on parents help, working out roles and barriers to FCC. The parental and children's perspectives will be examined later in this review, whilst this section will report and discuss the nurses (n=18) perspectives. All of the nurses were aged between 24 and 32 years and had at least two to eight years experience in children's nursing.

Under the theme of expectations, nurses viewed FCC as essential for children's welfare and parental presence as beneficial for the child. This echoes previously discussed studies and demonstrates a key principle of FCC identified by Shelton and Stepanek (1994). Nurses also identified the difficulty they have in giving constant attention to children under their care. This is elaborated in the second theme, relying on parents. Nurses felt that, due to other demands of their role, they depend heavily on parents to deliver "basic cares", which they define as usual parenting and child care such as washing, dressing, feeding and comforting the child. However, this makes the assumption that all parents carry out these cares normally, which may be an example of the socialised ideals Darbyshire (1995) refers to. However, under the same theme, nurses felt that it was important to give parents a choice about how they participate in their child's care as they felt that FCC might place unrealistic expectations on families. This suggests that nurses are aware of the dangers of socialised ideals of families (Darbyshire,1995). Coyne (2015) suggests may be nurses and parents appear to work out their caring roles in an unplanned manner rather than from a discussion of expectations. This challenge in role negotiation is a common theme across the studies examined so far in this review.

Nurses also reported that their willingness to allow parents to participate was dependent on certain conditions, such as, length of stay, chronic illness and parental competency, which was viewed as their ability to safely perform clinical aspects of care. According to Coyne

FCC IN CHILDREN'S NURSING

(2015), when these conditions were met, nurses facilitated parental participation in care; nurses appeared to direct care in general. This is contradictory to the view of the same group of nurses' that parents should be given a choice as to how they want to participate in their child's care. Even though nurses imposed these conditions, they felt that teaching parents the skills they need to be clinically competent was very time-consuming, but also felt that developing trust in parents abilities was important (Coyne, 2015). It seems the equilibrium proposed by Casey (Lee, 1998), between all those involved in a partnership, is controlled by the nurse.

The barriers to FCC identified by nurses included over-reliance on parents and lack of communication (Coyne, 2015). Nurses thought that over-reliance could cause conflict and stress with parents, but did not feel they were in a position to make a change for the better. On the topic of over-reliance, some nurses acknowledged that sometimes they do not assist with "basic cares" because they are so used to this being the parents' job. Darbyshire (1995) emphasised that children exist in a web of relationships and warned that generalising the roles of families creates challenges in FCC application. Most nurses blamed poor communication on a lack of formal documentation on parent's contribution to care. Some attributed it to pressured time and understaffing, whilst others viewed it as a problem caused by other nurses who were ineffective at assessing and negotiating (Coyne, 2015). Communication is identified as important for successful partnerships in FCC, by nurses in the majority of the studies previously discussed in this chapter and this demonstrates the key principles identified earlier in this review.

The first part of this chapter has examined nursing perspectives of FCC in children's nursing. Key perspectives revealed in these studies have been compared and their links to the theoretical foundations of FCC have been discussed. There is an agreement that the presence of parents and family is beneficial for the child and the principle that the family is constant in the

FCC IN CHILDREN'S NURSING

child's life is illustrated by nursing perspectives. This in itself demonstrates the evolution of children's health care, since the work of Bowlby, Robertson and the Platt Report. Some notable findings from the literature include the view that attitudes influence the application of FCC to practice. Another finding and a common theme among the studies, was the issue of role identification, which relates to both the key principles of FCC and Casey's (cited in Lee, 1998) theory of partnership. Despite the importance placed on roles and responsibility identification in theory, there are obvious challenges in practice in explaining the roles of those involved in FCC. Casey's partnership model (Lee, 1998) is also reflected in the nursing perceptions of positive actions in a partnership. Casey encouraged equilibrium between all those involved in a child's care. However nursing perceptions of positive outcomes of parental participation seem to contradict this as the outcomes include parents learning what is expected of them and parents conforming to social order (Coyne, 2008a). Nearly a decade before these studies were conducted, Darbyshire (1995) warned that the problematic application of FCC is a result of these 'socialised ideals' that nurses have towards families of sick children. This is linked to another finding, the over-reliance on parents as a result of demands of the nurse's job as well as the expectation by nurses that parents complete certain cares for the child (Coyne, 2015). However, it is also clear from the literature that nurses can control the extent to which families provide care for their child and have the ability to increase the families responsibilities as they prove their competency (Coyne, 2015).

It is clear that nursing ideas and application of FCC are not aligned with important theory and illustrate concerns raised in earlier literature (Darbyshire, 1995; Jolley & Shields, 2009). These inconsistencies contribute to a theory-practice gap and offer a method of improving the

application of FCC to practice. However, it is important to examine the perspectives of families and compare the findings to nursing perspectives.

Family Perspectives

When investigating FCC in practice, another fundamental perspective to examine is that of the family. When exploring this, it is important to take notice of a number of aspects, including how these perspectives compare to those of the nurses and how they relate to important theory. All of the following studies include parents as participants. In the following study (Hughes, 2007) only mothers responded.

Hughes (2007). Hughes (2007) utilised a descriptive survey to examine the attitudes of nurses and parents towards the use of a partnership model of care; the nursing attitudes are described in the previous section of this chapter, and will be referred to in order to compare the findings. The study was conducted in a children's unit at an Irish General Hospital and parent participants to return the survey were mothers, with no fathers or other family members responding.

All parents (n=43) in the study felt included in caring for their sick child, but over half (n=24) revealed they did not know what was expected of them when their child was admitted to hospital (Hughes, 2007). This issue of role identification was voiced by nurses in the same study, as discussed previously in the chapter and is a common theme amongst the studies examined so far. However, Hughes (2007) does not include information on the parents' understanding of the nurse's role.

Only a small number of mothers (n=12) thought the nurses were good at teaching parents new skills, despite over half of the nurses thinking they were good at this. This suggests that the

FCC IN CHILDREN'S NURSING

nurses may not be acknowledging the specific needs of the parents, which may be due to an underestimation by nurses of the complexity of the family (Darbyshire, 1995). It also may be due to the time pressures of the nurses role, an issue highlighted by nurses in studies in the previous section of this chapter (Coyne et al., 2011; Coyne, 2015). Another possible explanation is a need for up-skilling in nurses' teaching skills. The majority of parents (n=39) felt that they were provided with sufficient verbal information about their child's care, however a smaller number (n=21) felt there was not sufficient written information on the ward to meet parent's needs. Communication was identified by nurses as essential in partnerships and it is a key principle of FCC proposed by Shelton and Stepanek (1994) who advocate for a need for the exchange of complete information between families and health professionals.

Many parents (n=40) agreed that the visiting policy was family friendly, but over half (n=25) viewed the costs of staying in hospital with their child as too high (Hughes, 2007). While twelve of the parents felt that the facilities provided to them at the hospital were comfortable, thirty were not satisfied with the facilities that were available. The issues of cost and hospital facilities were discussed by nurses in the study by Coyne et al. (2011), who identified that to enhance FCC, improvements in facilities and financial supports were necessary. Shelton and Stepanek (1994) proposed that a key principle of FCC was ensuring support systems are accessible, flexible and comprehensive.

As identified previously, the use of a questionnaire to assess perspective and attitudes may not be the most appropriate method for this study. Hughes (2007) utilised closed-ended questions, which did not allow for elaboration of ideas. This survey was only conducted in one children's unit in one hospital and as a result the findings cannot be generalised (Hughes, 2007). However, the response by mothers only, may be reflective of the norm in children's wards.

FCC IN CHILDREN'S NURSING

Darbyshire (1995) discussed the potential marginalisation of some family members due to nurses' socialised ideas of what constitutes family. Only mothers as participants in Hughes' (2007) study, may be reflective of marginalisation, particularly of fathers and other family members, resulting from nurses' socialised views of family relationships. However, fathers and other family members were given the opportunity to participate, but did not respond.

Nevertheless, this lack of response may be a result of reluctance, due to marginalisation.

Darbyshire (1995) describes this as an issue of kinship.

McDowell, Duffy and Parkes (2015). McDowell, Duffy and Parkes (2015) aimed to assess healthcare use and perceptions, about FCC, of the 123 families of children and young adults with severe cerebral palsy. Data was collected using the Measure of Processes of Care-20 (MPOC-20), a questionnaire used to measure perceptions of FCC in the context of five areas: enabling and partnership, providing general information, providing specific information about the child, coordinated and comprehensive care and respective and supportive care. For each of the 20 items included in these domains, families rate the "family-centredness" of their experience on a scale from 'not at all' to 'to a very great extent' (McDowell et al., 2015, p. 2). Siebes et al. (2007) verify this tool and suggest it is a reliable method of assessing perspectives.

The majority of the domains (enabling partnership, providing specific information, coordinated and comprehensive care and respective and supportive care) were all scored moderately, which infers that each domain was witnessed by families to a moderate extent. This demonstrates that the important principles, identified by Shelton and Stepanek (1994) and Kuo et al. (2012) are evident in FCC practice in this setting. These principles include, facilitating family-professional collaboration, respect and honouring differences. However, the domain of

FCC IN CHILDREN'S NURSING

providing general information, scored poorly, which may suggest that the sharing of information is not as complete as Shelton and Stepanek (1994) proposed in their list of key principles governing FCC. Over 70% of the participating families felt that they would like more general information about things, including services available to them and their child, their child's condition, how to access information for themselves and/or contact other parents and families.

In this study, family perspectives were based on experiences they had with a young family member in hospital. The participants included the children and young people with cerebral palsy (4-11 years, 12-18 years, 19-27 years). However, McDowell et al. (2015) analysed the variance in the results to reveal no significant difference between the age groups that participated and therefore between children and young people. One criticism that should be mentioned is the use of a survey-like method. McDowell et al. (2015) states that part of their aim was to assess family perception, although the MPOC tool has been labelled as an effective way to measure aspects of FCC (King, King & Rosenbaum, 2004), this way of data collection is limited to the questions of the MPOC and does not allow for expansion on answers and ideas; focus groups or interviews may have been more appropriate (Barriball & While, 1994). Despite this, the survey design is used in many other studies to determine perspectives of those involved with FCC (King, King & Rosenbaum, 2004).

Coyne (2015). Coyne (2015) utilised in-depth interviews to explore parents, children and nurses' perspectives and experiences of FCC and gain an understanding of roles and relationships and how they are negotiated. The parent participants (n=18) were aged between 33 and 46 and were a mix of professionals and housewives (Coyne, 2015). Coyne (2015) identified four main themes; expectations, relying on parents help, working out roles and barriers to FCC.

FCC IN CHILDREN'S NURSING

The children's perspectives in this study will be discussed in the next chapter. Coyne's (2015) use of in-depth interviews allowed for elaboration of ideas through open-ended questions followed by probes, reflection and paraphrasing.

Under "expectation", parents (n=18) agreed their presence in the setting was crucial and beneficial to their child's health, which was supported by nurses. Parents appreciated that the nurses could not be present at all times and therefore viewed parental help as essential. The 'relying on parents' help' theme revealed that parents expected to join in with their child's care and continue with normal child care. This is an important feature of Casey's (cited in Lee, 1998) model of partnership, which advocates for a balanced contribution by the family, to the child's nursing. It also demonstrates collaboration between families and health professionals, which Shelton and Stepanek (1994) identified as a key element of FCC. Parents viewed their roles as helping the busy nurses and making sure their child received acceptable care. In terms of working out roles in a hospital environment, parents voiced concern of a lack of information about roles and how their role and the nurses' worked together. This challenge of role identification was also identified by nurses and may be due to poor communication, which has been identified in many studies in this chapter as a barrier to FCC and partnership (Coyne, 2008a; Coyne et al., 2011; Hughes, 2007).

Parents stated that often, the nurses' expectations of them were discovered through asking other parents and observing the nurses for a while, at the beginning of their child's admission. Parents reported that they sensed a change in their relationships with nurses after a while, as they would be invited to participate more frequently, once it appeared that they gained the trust of the nurses. It has already been identified that nurses view this as parents showing competency of clinical skills and, therefore, knowledge (Coyne, 2015).

FCC IN CHILDREN'S NURSING

Parents reported that the two main barriers to FCC were over-reliance on parents and a lack of communication. These views matched those of nurses participating in the same study. In addition, parents stated that they would sometimes be afraid to complain or voice concern, in case it negatively affected their child's care (Coyne, 2015).

The last part of this chapter has investigated family perspectives of FCC. The studies have revealed views of FCC that both mirror and contrast to those of nurses. Families viewed their presence with the unwell child as beneficial for the child's health. Many parents in the studies emphasised interest in contributing to their child's care by helping out wherever possible, which is representative of Casey's (Lee, 1998) views of equilibrium in a partnership. However, a common theme throughout the studies was the challenges parents feel in identifying their role when caring for their unwell child; this was also identified by nurses previously in this chapter. In one study (Hughes, 2007), parents acknowledged that they only grew to understand their role by talking to other parents; this infers challenges in communication between nurses and families, another common theme between nursing and family perspectives.

Both nurses and families have identified that communication is needed for successful partnership and parents think it could be improved. Parents also identified that over-reliance on them by nurses, creates problems in partnerships but at the same time felt that they need to gain the trust of the nurse before helping to care for their child. As has already been discussed, nurses acknowledge that they allow parents to participate more once they have shown they are competent and therefore have the knowledge to care for their child safely.

Considering both the nursing and family perspectives that have been examined in this chapter, it is possible to draw some conclusions. Darbyshire's (1995) views of the over-simplification and unrealistic views of families have been demonstrated in practice in current

FCC IN CHILDREN'S NURSING

literature. Socialised ideals of families may have caused the challenges in role identification and are acknowledged by both nurses and families in these studies. The challenge of role identification is a significant theme of this chapter and for that reason should be considered in the context of the theory practice-gap. As well as this, communication is also a common theme, identified by theorists (Shelton & Stepanek, 1994; Lee, 1998; Jolley & Shields, 2009) as an essential aspect of FCC, particularly in partnerships, participation and negotiation.

It is appropriate now, in this review, to move away from nursing and family perspectives of FCC to focus on the child.

Chapter Four

Children's Perspectives

The voice of the child merits its own critical examination in this review. It could be argued that the lack of primary research focusing solely on children's perspectives, is in itself a very significant gap contributing to the challenges of FCC in practice. Bricher (2000) suggests that one reason for this lack of research may be ethical concerns about carrying out research with children. Whatever the reason, the child's voice is important to consider in this review.

Pritchard Kennedy (2012). The child's voice was the focus of a study by Pritchard Kennedy (2012), which allowed children to "define how they understand their partnership role in FCC and recommend FCC strategies" (Pritchard Kennedy, 2012, p. 863). The children in this study all had bleeding disorders (n=4) or other chronic illnesses (n=4) and were aged between seven and eleven years. They were all receiving outpatient care in an area governed by a Western Canadian children's hospital. The study used an ethnographic approach, which included; unstructured interviews exploring children's understanding of FCC, document review to provide institutional context, and validation interviews with some of the participating children, to generate FCC recommendations (Pritchard Kennedy, 2012).

From the findings of the interviews with the children, seven key domains of FCC were identified; my best interests, virtues, talking and listening, being involved, knowing, making decisions and being connected. Recognising the best interests of children was highlighted as an effective starting point for FCC; the children believed that this provided a base for good communication trust, informed decision-making and collaborative teamwork. This echoes

FCC IN CHILDREN'S NURSING

several of the key principles of FCC, highlighted by Shelton and Stepanek (1994) and reiterates Casey's (cited in Farrel, 1992) view that successful partnership is beneficial for the child's health. Children reported that they relied heavily on their parents to ensure these best interests were correctly identified and maintained (Pritchard Kennedy, 2012).

Four character qualities were identified by children as essential virtues for effective FCC for all those involved; respect, trust, trustworthiness and doing our best work. As part of respect, children emphasised "being nice" and expected FCC partners to "stick up for" their best interests and "do what they say they are going to do" by "keeping promises" (Pritchard Kennedy, 2012, p. 866-867). "Doing our best work" was acknowledged as "working hard and getting things done on time, doing your best work so you can be proud" (Pritchard Kennedy, 2012, p. 867).

Children recognised their important role in sharing health experiences with other children, families and nurses; they expected FCC partners (identified as children, parents, caregivers and nurses) to take the time to talk and listen to them and each other (Pritchard Kennedy, 2012). This identifies that the children place importance on communication. However, the children also identified that "adults" had different communication rules and gave the example that adults interrupt each other. Children also stated that they believed it was rude to interrupt adults when they are talking, which left them confused about how to participate in conversations about them. To address this, the children suggested group discussions, where everyone followed the same rules of talking and listening, so "everyone would get a turn" (Pritchard Kennedy, 2012, p. 867). This could be one solution to poor communication, identified in both nursing and parental perspectives, in the last chapter.

The children who participated recognised the context-specific roles of those involved in their care and recommended clear definition and communication of these roles, taking into

FCC IN CHILDREN'S NURSING

account “the child’s best interests, collaborative processes, responsibility and accountability” (Pritchard Kennedy, 2012, p. 867). The inclusion of these aspects may help understanding of roles and improve the “ad hoc” (Coyne, 2015, p. 802) way in which nurses and families are negotiating their roles in caring for the ill child.

Under the other domains, children recognised the importance of their own knowledge and participating in their own decision-making (Pritchard Kennedy, 2012). Children could distinguish between different types of decision-making, including making decisions themselves, making decisions with others and others making decisions for them. Children also recommended that training should be available for all FCC partners, including themselves, on working together in an effective team; one child stated “just because you are on a team, doesn’t mean that you’re good at it” (Pritchard Kennedy, 2012, p. 867).

Pritchard Kennedy (2012) used document review to determine where the domains revealed in the study corresponded to legislation and policy. The biggest gap found was a lack of clarification of roles in the FCC partnership, in policies at both a regional and institutional level. Role identification was a common theme among all groups in all of the studies in this review. It may be a key aspect to closing the gap between theory and practice in FCC.

The validation interviews resulted in a number of recommendations made by children (n=4), to support their role in FCC. The first was the use of a “Treasure Map” of the different domains of FCC (my best interests, virtues, talking and listening, being involved, knowing, making decisions and being connected). The children pointed out that interest and understanding of FCC could be enhanced with the use of vibrant colours and clear connections and suggested that the way adults perceived FCC was “boring” (Pritchard Kennedy, 2012, p. 868). Children also suggested an all-ages interactive workshop, involving the aforementioned treasure map, to

FCC IN CHILDREN'S NURSING

improve everyone's understanding of the FCC partnership. The children also visualised the treasure map to be used as a game that could be played with family and friends, where the player would have to solve problems to gain keys to the next step of the treasure map, until they had gained all the knowledge they needed about FCC (Pritchard Kennedy, 2012).

Although this study provides valuable insight into the child's perspective of FCC, it only involves a small group of participants (n=8) and cannot be deemed to represent the population of children involved in FCC. The participants in the study either had bleeding disorders or other chronic illness, however the findings do not differentiate between the conditions. It may be significant to explore the differences in perceptions of children with different diagnoses.

Coyne (2015). Under four themes (expectations, relying on parents help, working out roles and barriers to FCC), Coyne (2015) reveals some important views of participating children (n=18). In-depth interviews were conducted in the hospital at convenient times for participants (Coyne, 2015). Play and discussions about hobbies and interests were used by the researcher, prior to starting the interviews, to reduce anxiety and build rapport (Coyne, 2015). Much the same as nurses and parents, the children, aged seven to sixteen years old, viewed their parent's presence as important to their time in hospital and valued their help (Coyne, 2015).

One major point of this study, highlighted by Coyne (2015), is that children can identify the different roles of their family and the nurses; these roles differ depending on the individual child's needs. Children preferred their parents to stay and help with usual cares, as their presence made them feel less frightened. The children also reported that they relied on their parents to talk to the health professionals on their behalf. This relates back to the foundations of FCC and the work of Bowlby and Robertson, which emphasised the need for parental presence to improve an

FCC IN CHILDREN'S NURSING

unwell child's wellbeing (Alsop-Shields & Mohay, 2001). According to Coyne (2015), children preferred nurses to carry out any technical or medical procedures, or any procedures that may be painful, as they were seen as the experts. This clearly identifies a significant part of the nurse's role, as perceived by children. Casey (cited in Jolley & Shields, 2009) suggests that part of this nursing role in partnership is also teaching parents and children so they can participate in cares. With this in mind, Coyne (2015) reported that children were willing to learn and have their parents learn cares that would be required at home, if it meant they could get home faster. Despite this, in the previous chapter of this review, Hughes (2007) reported that some nurses felt they underestimate what parents' can learn to do for their un-well child. This is where the need for improved communication, as identified by parents in the last chapter, may be beneficial. One other similarity to family perceptions in this study was that children identified cost as a barrier to FCC, stating that they were aware of the costs for parents who stay with their child and the challenges this can create.

This study gives significant insight into the perspectives of children on the topic of FCC. The use of comparisons and contrasting of three different groups of perspectives (nurses, parents and children) is revealing of both negative and positive application of FCC. Coyne (2015) builds on the findings of the study by presenting recommendations for practice. These include skills training in assessment, role clarification, facilitation and reflection to help them work in partnership with families (Coyne, 2015).

An examination of the perspectives of children on FCC is necessary to include in this review. Just like the nursing and family perspectives, children supported the idea that successful partnership and FCC were beneficial for the child. The studies in this chapter suggest that despite challenges in role identification amongst nurses and families, children have clear views of what

FCC IN CHILDREN'S NURSING

the role of those involved in their health care should be. Pritchard Kennedy (2012) referred to context-specific roles, which children seemed to understand better than nurses and families.

Another significant theme was communication and the need for improvements between all those involved in the child's care. Children identified the importance of communication to them as well as the challenges they face in communicating with "adults".

Chapter Five

The Child's Voice

Summary So Far. This review of the literature so far has exposed a number of main points that are worthy of further discussion. Early on, the review identified that the concept of FCC has evolved due to a need for more appropriate and acceptable methods of caring for children. The theoretical foundations of the concept are well documented and feature in literature spanning decades. However, it is clear from a critical examination of current literature that the implementation of these theories is not straightforward. Darbyshire (1995) warned of an unrealistic perception of FCC that avoids criticism and later academics have revealed that this indeed does exist in children's nursing today (Coyne et al, 2011; Shields, 2010; Shields, 2005; Franck & Callery, 2004; Shields, Pratt & Hunter, 2005).

This unrealistic view is demonstrated in current practice by research into nursing perceptions of how partnership models are being practiced. Nursing perceptions in the literature have revealed that socialised ideals exist amongst nurses, as well as perceived positive outcomes of partnership, which do not reflect important theoretical principles (Coyne, 2008a). This may suggest that these theoretical foundations have become outdated. However, it also highlights that attitudes have a significant impact on FCC application, affecting aspects such as parent education and communication (Lee, 2007). This is supported by research into family perceptions, which show that parents often do not express that they understand what their role is in caring for their child and how this role works alongside the nurses'.

It is evident from different perspectives that a theory-practice gap exists within the concept of FCC. Despite a plethora of literature on theoretical foundations to guide practice, there are clearly challenges in the application of FCC to children's nursing. Examining children's

FCC IN CHILDREN'S NURSING

perspectives on FCC in children's nursing supports this, but also highlights possible solutions to these challenges, such as the aspect of role identification. With this in mind, the final chapter of this review will explore the importance of the child's voice and its relevance to FCC. This will involve an examination of children's voices in the context of children's nursing, the rights of the child and children's participation in role identification in decision-making.

What is Voice? McPherson and Thorne (2000, p. 22) suggest that "the notion of voice is a metaphoric representation of expressed will or intent". In the context of the child it is "the transparent transmission of thoughts and feelings from the child's inner world to the outer world" (McPherson & Thorne, 2000, p. 23). McPherson and Thorne (2000) also suggest that different perspectives of voice exist based on the characteristics of children. These characteristics are related to stages of human development that determine the development and expression of messages. For example, a child who is frightened may not be able to verbally communicate their emotions, however a nurse may be able to identify these emotions through body language (McPherson & Thorne, 2000). In other words, the child's voice is multi-dimensional. Considering this, McPherson and Thorne (2000) propose that a fundamental part of the children's nurses' role is to recognise the different dimensions of the child's voice, such as words, sounds, body language and even silence. This view of the children's nurses' role is supported by Livesley and Long (2013), who recommend further research be done into recognising and interpreting these dimensions of the child's voice and, therefore, understanding the child's needs.

Livesley and Long (2013) suggest that children's views are not recognised due to the unfit tools used to assess and provide nursing care. McPherson and Thorne (2000) suggest that nurses

may not recognise different dimensions of the children's voice due to simplistic and misrepresentative interpretations of children's communications. This simplification of the child's voice mirrors nurses' simplified views of family relationships, identified by Darbyshire (1995) previously in this review. McPherson and Thorne (2000) propose that children's nurses must develop skills that help them recognise the child's voice, as well as when it may be absent, and must resist the temptation toward overly simplistic interpretations. Livesley and Long (2013) identify that this skill development will also aid children's nurses in recognising children's competence.

Rights of the Child. When considering the child's voice, it is appropriate to examine the rights of children, in particular, their right to be heard. The United Nations Convention on the Rights of the Child (1989) is a set of standards for children's rights that are recognised throughout the world (Hart, 2002). Many countries use this set of rights as reference points for their own policies; New Zealand has utilised them to develop area-specific policies in many aspects of health care for children and young people (Canterbury District Health Board, 2011).

The articles that are most relevant to this review are Articles 9, 12, 13, 24 and 25. Article 9 states that children must not be separated from their parents against their will, unless it is in their best interests (UNICEF UK, 2015). Child health care has evolved to meet this standard, from a time when parents were not permitted to be with their child in hospital, before the work of Bowlby and Robertson and the impact of the Platt Report (Jolley & Shields, 2009). Article 12 is fundamental in the emphasis on the rights of the child to be heard (Hart, 2002). This states that every child has the right to express their views, feelings and wishes in all matters affecting them and to have their views considered and taken seriously, at all times (UNICEF UK, 2015). This

FCC IN CHILDREN'S NURSING

emphasises, the fundamental role children have in their own health care. Article 13 is similar as it considers freedom of expression as well as children's right to access all kinds of information, within the law (UNICEF UK, 2015). Articles 24 and 25 relate directly to health care. Article 24 states that every child has the right to the best possible health, which Bowlby and Robertson suggest entails the presence of parents and family (Jolley and Shields, 2009). Article 25 states that if a child has been placed away from home for the purpose of care or protection, they have a right to regular review of their treatment, the way they are cared for and their wider circumstances (UNICEF UK, 2015). This supports the importance of the child's voice in decision-making and therefore FCC and partnerships in children's nursing. The importance of the child's voice has been made clear, with identification of the rights of the child and acknowledgement of the need for improvement in recognising the expression of children's thoughts and feelings. With this in mind, the place of the child's voice in FCC needs to be addressed. An example of this is the child's ability to identify the roles of those involved in his or her care.

Role Identification. Both studies presented in the last chapter (Coyne, 2015; Pritchard Kennedy, 2012) examined children's perspectives and experiences of FCC. The main finding to be brought forward from both studies is the identification of roles. It is evident from both nursing and family perspectives that identification of roles in FCC presents challenges, however this challenge is not reflected in the children's perspectives. Therefore, it is possible to argue that the child's voice may be a way forward in overcoming this challenge. Both Coyne (2015) and Pritchard Kennedy (2012) reported that the children in their studies could identify the different roles their parents, family and the nurses played in their care. Pritchard Kennedy (2012) suggests

that role identification is context-specific and as a result, different for every child. If this is the case, the role that each person plays when caring for a child should not only depend on that child's needs, but what the child states he or she wants from each person. It has already been identified that the child's voice can be expressed in a number of ways (McPherson & Thorne, 2000; Livesley & Long, 2013). The identification of a need for improvements in recognising these different expressions is relevant here, as children may identify the roles of those involved in their care in a number of different ways including words, sounds and body language (McPherson & Thorne, 2000). The role of the child's voice in role identification emphasises its importance in children's nursing and as a way of overcoming the challenges presented by FCC.

The topic of decision-making in children's nursing has not been addressed so far in this review, however, this also emphasises the importance of the child's voice in children's nursing.

Decision-Making. Shared decision making is important in FCC, and Shelton and Stepanek (1994) suggest that this forms a large part of their key principle, information-sharing. Moore and Kirk (2010) suggest that children should have the same rights to involvement in decision-making as adult partners and emphasise the importance of autonomy of children. Just as the child's voice is necessary in role identification, it may also be vital in decision-making. However, on investigation of the literature on children's participation in consultation and decision-making, Coyne (2008b, p. 1684) concluded that the views of children are rarely acknowledged and children hold 'marginalised' positions in healthcare encounters. Darbyshire (1995) identified this marginalisation in FCC, which is also apparent in the participant response of a study investigating parent perspectives of FCC (Hughes, 2007), in which only mothers

responded. This marginalisation may also be reflected in the limited research on children's perspectives.

Coyne (2008b) identifies factors that hinder children's participation in decision-making, which include health professional's communication styles and behaviours. This is a significant link to the findings of the previous chapter, in which poor communication was identified, by both nurses and families, as a major barrier to FCC and partnerships. Children in the study by Coyne, (2008b) also identified other obstructions to their participation, including not knowing health professionals; not wanting to hear bad news; fear of causing trouble by asking questions; lack of time with health professionals; being ignored; being disbelieved; difficulty contacting health professionals; health professionals not listening; difficulty understanding medical technology and parent's actions.

Coyne (2008b) points out that parents and health professionals facilitate children's participation in care but also suggests that many are not doing so. Coyne (2008b) proposes that more research be done in order to explain this behaviour of parents and health professionals. This lack of acknowledgement of the child's voice is evident despite worldwide recognition of the rights of the child, which includes their right to be involved in their treatment. Coyne (2008b) points out that it is important to consider those children who may prefer a passive role, as they must still be given the opportunity to participate.

Although decision-making is an important aspect of partnerships and FCC, the child's participation is not well supported in the literature. Much of the literature regarding FCC focuses on the relationship between the family and the health professionals and how this affects the child, which is evident in the studies examined in this review. However, the focus may require a shift

towards the child and Franck and Callery (2004) suggested, over a decade ago, that more heed should be given to the child's involvement in their own care.

Where To From Here? The FCC literature examined throughout this review has exposed a number of challenges in the application of FCC in children's nursing. Perspectives have been examined across a number of contemporary studies and the relationship between the nurse and family has been discussed in relation to challenges such as attitudes, communication and roles. These challenges have been related to important theoretical foundations to illustrate that a theory-practice gap does indeed exist and can be explained. This is important to consider when suggesting improvements for the application of FCC to practice and aspects such as attitudes, communication and role identification are identified as starting points for change. The child's view may hold further insight as to how to begin making these changes to FCC in children's nursing. Despite this, recognition and understanding of the child's voice is in need of improvement and nurses play an important role in this (McPherson & Thorne, 2000). Improvements in recognising and understanding the child's voice may involve a shift in focus from the family to the child (Franck & Callery, 2004), which may move the attention of children's nursing away from Family-Centred Care.

Franck and Callery (1994) suggest that this shift is the difference between Family-Centred Care and another model of care, Child-Centred Care (CCC). Franck and Callery (1994) propose that to choose between one or the other is an indication of the extent to which children's concerns should be reflected in their care. Soderback, Coyne and Harder (2011) support the shift to CCC and suggest that this model of care acknowledges the rights of the child, particularly in

FCC IN CHILDREN'S NURSING

terms of health care; it has already been established that the rights of the child are relevant to children's nursing (UNICEF UK, 2015).

If a movement to Child-Centred Care is to happen, children's nursing needs to adapt and develop new skills and ways of thinking. Firstly, recommendations made to improve acknowledgement of the child's voice, should be considered. Both McPherson and Thorne (2000) and Livesley and Long (2013) suggest that actions must be taken to improve nurses' recognition and understanding of the many dimensions of a child's 'voice'. This may call for changes in nursing education, at both pre- and post- registration levels, to improve competency in this area. As part of recognising the child's voice, McPherson and Thorne (2000) recommend that more research be undertaken in order to understand the different needs of children and the multitude of signals they give. Soderback et al. (2011, p. 100) suggest that competency is also necessary in the areas of child development, life conditions in general and knowledge about the specific child in specific situations. Children's nurses will also need to be competent in their knowledge of children's rights and be able to understand how the individual child's perspective relates to their nursing practice and the child's situation (Soderback et al., 2011, p. 100); this may also involve improvements or changes to nursing education.

Franck and Callery (2004, p. 269) emphasise the difference between FCC and CCC, as neither concept can exclude the other; CCC must take into account the social environment of the child and the main concern of FCC must be the health of the child. Further research could be done to establish the nursing of families and their role in Child-Centred Care, as the attributes of FCC should not be disregarded.

This review leaves room for further examination of CCC and its collaboration with FCC in practice. It may be necessary to compare the models in practice and identify possible

FCC IN CHILDREN'S NURSING

differences in the outcomes, or how the challenges of FCC may be combatted using Child-Centred Care.

Conclusion

This literature review has examined the literature on FCC in order to identify and explain a theory-practice gap. Firstly, the theoretical concepts of FCC were discussed, with identification of important definitions and key principles that are useful in the assessment of FCC today. The history of children's nursing and important influences on models of care were also discussed before a view of FCC today was identified. This view suggested the presence of a theory-practice gap within FCC. An examination of this gap was performed using primary research, which gave insight into the perspectives of those involved in FCC in practice. Nursing and family perspectives revealed a number of challenges in FCC practice. Nurses acknowledged the effect of negative attitudes and the importance of communication in a partnership. Parents identified poor communication by nurses as a challenge they faced when trying to care for their unwell child. Across both nursing and family perspectives, the challenge of role identification stood out as a common theme in FCC application. This theme was also identified in children's perspectives, however the studies reviewed suggested that challenges, such as role identification, may be combatted by children's views. This introduced the topic of the child's voice to the discussion. The importance and relevance of the child's voice in children's nursing was established using the rights of the child and an explanation of the concept of 'voice' in the context of the child. The role of the child's voice was situated in the identification of roles and decision-making. From here, it was determined that acknowledgement of the child's voice is in need of improvement, which may entail a shift in the focus of children's nursing from a family-

FCC IN CHILDREN'S NURSING

centred model, to a child-centred model. The concept of Child-Centred Care was introduced and recommendations were suggested for the implementation of this model to children's nursing.

Lastly, recommendations were made for further research that may be facilitated by this literature review.

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