Nurses’ Perceptions of Family Centred Care in the Neonatal Intensive Care:

A Review of Available Instruments

by

Colleen Backlin

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Supervisor: Dr. Lenora Marcellus

Committee Member: Dr. Karen MacKinnon
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Introduction

The practice of neonatology has evolved significantly since I first started my nursing career just over 20 years ago. Great strides have been made in the way that we care for our often very tiny patients. Not only have we become more aware of the long term physical effects that a neonatal intensive care unit (NICU) stay can carry for infants and children, but we are also more cognizant of the psychological, social, and emotional risks that result from hospitalization. Recognition of the importance of family in the lives of these children has grown alongside the many technological advances that have taken place in the care of ill newborns.

Family centred care (FCC) is purported to be best practice in healthcare, particularly in the care of infants and children (Abraham, 2012; Jolley and Shields, 2009). While I believe that there is a desire on the part of neonatal nurses to provide excellent care to their patients, full implementation of the principles of FCC has not yet become daily practice in many NICUs.

In this paper I provide a brief overview of FCC and some of the historical background that has influenced the development of FCC practices. The perceived benefits, the challenges, and the divergent views of FCC will be discussed. I report on an integrated literature review that I conducted to identify existing instruments that are designed to measure nurses’ perceptions and practices of FCC. Finally, I will provide rationale for the choice of instrument that I feel is most appropriate for use in my clinical setting.
Background to the Philosophy of Family Centred Care

History of Family Centred Care

The separation of infants from their families, particularly their mothers, was unusual in North America until the early part of the 20th century when hospital deliveries became more common. Early medical efforts to care for premature babies meant that babies were separated from their family for extended periods of time. Little acknowledgement of potential bonding issues appear in the literature between Budin’s acknowledgement of the importance of the role of mothers in 1900 through to the 1960s (Baker, 2000; Philip, 2005). The separation of child and family was not a phenomenon exclusive to neonates. Jolley and Shields (2009) note that in the United Kingdom until the middle of the 20th century, children that were admitted to hospitals often saw their parents for only half an hour a week, or sometimes not at all.

Authors differ as to what, or who, was responsible for the move toward FCC. Some authors suggest that World War II had a significant impact on the development of FCC (Jolley and Shields, 2009). Throughout Europe many children were separated from their families during the war and the psychological effects of this separation on the children were recognized by professionals at that time. Exploration of the effects of separation then expanded to include the separation of hospitalized children from their families. In particular, in the mid 1940s John Bowlby, a British child psychiatrist, and James Robertson, a British social worker, widely publicized their work on the effects of child and parent separation (Shields, 2010). A committee set up by the British government commissioned the Platt Report (1959) which presented the findings of a study of hospital care for children (Jolley and Shields, 2009). Among other things, the Platt Report recommended unrestricted visitation for mothers of hospitalized children (Shields & Tanner, 2004).
Several key theoretical perspectives contributed to early development of FCC. Bamm and Rosenbaum (2008) credit the work of American psychologist Carl Rogers with starting the transition to FCC in the United States. In the 1940s, Rogers developed client centred therapy as a mental health intervention, an approach that created considerable interest during that time. The Association for the Care of Children in Hospital (ACCH), a U.S. based parent advocacy group adapted Roger’s therapeutic approaches for children and families and promoted them for use in paediatric hospitals. The perspective that FCC is viewing the child as part of the family system generally draws on the 1968 systems theory of Von Bertalanffy (Bamm & Rosenbaum, 2008). This perspective when combined with Bronfenbrenner’s 1979 ecological theory of child development emphasized the powerful role that family has in a child’s life.

In the United States, beginning in the late 1960s, further development of the philosophy and practice of FCC is often credited to the strong advocacy of families of children with chronic health concerns (MacKean, 2005). The efforts of former Surgeon General Everett C. Koop to include families are recognized by several authors as being a major impetus in the development of FCC (Johnson, 2000). Public demands and consumer pressure in the US prompted the introduction of numerous laws including the Education for All Handicapped Children Act in 1975, the Family Preservation and Family Support Act in 1993, and the Families with Disabilities Act in 1994 (Johnson, 2000). These acts all stressed the inclusion of family, rather than just professionals in the planning and care of children. By the early 1980s the Maternal and Child Health Bureau was working closely with families of children with healthcare needs to ensure that families had input and were active participants in the care of their children (Wells, 2011).
Although FCC appears to have been born out of developments in the care of children with chronic conditions in the United States, in other parts of the world it was more predominantly influenced by concerns about the care of acutely ill children in hospitals. In Canada, an early study of FCC took place in a paediatric hospital unit. Brown and Ritchie (1990) noted the apparent discrepancy between nurses’ beliefs about families and their practices with families. Internationally, additional cultural and societal pressures also played a part in the move toward FCC. Overall, there appears to be no single event or influence that can be credited as being the origin of FCC, rather it was the convergence of many factors and influences over time.

**Definitions of Family Centred Care**

There is an overwhelming body of literature available that describes and defines FCC. The following is a brief summary of several of the dominant themes that emerge when reviewing this literature, within the context of providing nursing care in a hospital setting to infants and children and their families.

One difficulty inherent in defining FCC is that each author writing on the subject of FCC tends to adopt their own definition as the primary definition of FCC. For example, the Institute for Patient and Family-Centered Care (IPFCC, 2010a) speaks to a partnership between healthcare providers, patients, and families that is mutually beneficial. Shields describes FCC as “a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person and in which all the family members are recognized as care recipients” (Shields et al., 2006, p. 1318). Shields gives the impression that her definition has been universally accepted as the true description of FCC when she declares that up until her definition of FCC was published in 2006, there had not been a stable definition of FCC (Shields, 2010).
Family Centred Care and Family Nursing

There is a large and growing body of literature on family nursing theory. These theories serve to shape both the research and practice of family nursing (Marcellus, 2006). Theories may provide a way for nurses to better understand families when used as guides rather than unbending truths (Doane, 2005). In this way, family nursing theory contributes to our perspectives of family nursing.

Segaric and Hall (2005) suggest that there are three prevailing perspectives of family nursing. The first perspective is one of viewing the family as context (Shelton, Jeppson, & Johnson, 1987). The second view is that of the family as the target of intervention, therefore care is planned to meet the needs of the family (Friedmann, 1989; Shields, Pratt, & Hunter, 2006). The third view is that of family as a system, and as such, the parts of the family are enmeshed in a way that the effect on an individual part of the family would affect the whole of the family (Bell, 2009). Although theoretically these perspectives appear to be discrete, in practice it is evident that the lines differentiating these perspectives are not clearly defined.

From the perspective that views family as context; nursing care is directed toward a patient, regarding the family as the background and as providers of support. Nursing care from this viewpoint does not hold the family itself as the recipient of care. Within this perspective of FCC, various authors have described different roles that family may play. Terms such as partnership, negotiated care, care by parent and participation used in descriptions of FCC suggest a continuum of involvement of parents and family in the care of children (Coyne, 1996).

Building on the ideas of Segaric and Hall (2005), the IPFCC definition more closely reflects the perspective of family as context; while that of Shields specifies that the family is the recipient of care. These differences in definitions, though at times subtle, can greatly contribute to the
confusion within writings on FCC, and consequently, contribute to challenges in operationalizing, measuring and evaluating FCC. Key concepts that underpin current understandings of FCC include: “partnership, collaboration, participation and communication” (Segaric and Hall, 2005, p. 213).

The context for care also influences the definition of FCC. For example, at times FCC in a non-acute setting is referred to as family-centred service (FCS). The CanChild Centre for Childhood Disability Research (2012) defines family-centred service in a similar manner to other definitions of FCC; however, CanChild emphasizes the family as an expert on their child (CanChild Centre for Childhood Disability Research, 2012). Another group of non-nurse researchers working in a community health sciences department in an Alberta university defines FCC as:

... placing the needs of the child, in the context of their family and community, at the center of care and devising an individualized and dynamic model of care in collaboration with the child and family that will best meet these needs (MacKean, 2005, p75).

It seems that the discipline of the authors and the context of care can influence how FCC is understood.

**Enactment of FCC**

Descriptions of FCC in the literature demonstrate that FCC varies in its enactment. Most significantly, differences in FCC reflect the context for care. FCC may be implemented differently in units such as a paediatric ICU, oncology, and NICU. The developmental stage of the child is another variable that influences how FCC is enacted, and whether the child is cognitively, developmentally and physically able to participate in their own care must be taken into consideration. As well, different aspects and degrees of FCC may be enacted depending on
whether the family is caring for a child with a short term, acute illness versus a child with a long term chronic health condition.

FCC has moved beyond its beginnings and is now being applied to more than paediatric care. To acknowledge the involvement of patients in their own care, the IPFCC’s name was changed to include the word patients in 2010. Prior to that time much of the focus of the institute was on paediatric patients, but a growing realization of the need for involvement of families in the care of adults was also acknowledged (IPFCC, 2010b).

**FCC in the NICU**

An important addition to the literature on FCC in the NICU was the work of Helen Harrison. Ms. Harrison, the parent of a child born prematurely, wrote about her experiences in *The Premature Baby Book* (Harrison & Kositsky, 1983). For many years this book was considered the “go to” book for families of premature infants. In 1992, Harrison organized a conference in Vermont at which principles of FCC for NICU care were developed (Harrison, 1993). Ten principles were drawn up by this council; many of them pertaining to the sharing of knowledge and collaboration between healthcare professional and families are similar to those developed by the ACCH (Shelton et al., 1987). It was a noteworthy development to have parents of infants who had been born prematurely play a key role in developing these principles. However, a significant limitation of this work was that the only healthcare members on council were physicians, leading to a lack of representation and voice for nurses (who provide the most sustained and close care for families), and other providers such as social workers (who have qualitative and emotional knowledge of family experiences).
Challenges with Enacting FCC

Despite the dramatic shifts toward FCC that have occurred in healthcare in the past few decades, continuing to strengthen this approach and philosophy within healthcare systems has not been without challenges. Not only have there been challenges in establishing what we mean by FCC in different contexts, but there have also been challenges in determining effective mechanisms for implementation of family centred care practices. Numerous studies have been undertaken to determine the perceptions of healthcare workers regarding FCC and their ability to put these beliefs and values into practice (Asai, 2011; Daneman, 2003; Paliadelis, Cruickshank, Wainohu, Winskill, & Stevens, 2005). Difficulties experienced when putting FCC into practice include: differences in expectations of FCC between healthcare workers and families and difficulty with role negotiation between families and nurses (Darbyshire, 1993; Shields, Kristensson-Hallström, & O’Callaghan, 2003).

The emphasis in nursing and healthcare on evidence based practice call into question the evidence that underpins the current practice of FCC. A 2008 Cochrane review on family-centred care failed to support the effectiveness of FCC because there were no studies that met the inclusion criteria of providing level I or level II evidence (Shields, Pratt, & Hunter, 2008). The lack of clinical trials is certainly understandable. In order to be included, studies needed to compare FCC with models of care that were not family centred (Shields et al., 2006). Given the general acceptance by healthcare professionals that non-inclusion of family is detrimental to the care of the child, it would seem unethical to conduct a study using this approach. Because Cochrane reviews favour quantitative evidence over other forms of knowing, it is unlikely that such a review will ever find sufficient evidence to support FCC even though a significant
number of qualitative studies have been conducted (Coyne, O'Neill, Murphy, Costello & O'Shea, 2011; Trajkovski, Schmied, Vickers & Jackson, 2012; Callery & Smith 1991).

Although most researchers, practitioners and policy makers agree that FCC is a desirable model of caring, significant challenges are apparent. As family involvement in the care of their children in hospital and community settings has increased, healthcare continues to be dominated by the medical model where healthcare professionals are often the primary decision makers of the treatment that a child receives. Healthcare providers also continue to be a controlling force that dictates the role that families may undertake (MacKean, 2005).

In summary, FCC is a well-accepted philosophy and approach to caring for neonatal and paediatric patients that has dominated academic healthcare writing for the past several decades. Despite being fraught with many challenges, FCC remains doggedly pursued as the standard of care that healthcare professionals, particularly nurses, seek to provide in their work. Though some providers and researchers may question the data supporting the use of FCC (Shields, 2010), most maintain that FCC is known intuitively as the correct way to practice (Abraham, 2012; Shields, 2010). At the present time, FCC is upheld as the standard of care in most, if not all, North American NICUs. Given this reality, I believe that it is incumbent upon nurses to enact FCC to the best of our abilities.

The Role of Nurses in FCC and the Context for this Project

FCC practices in an NICU are unique in several respects. Generally an infant is admitted to a NICU prior to the baby’s family having the chance to become acquainted to the newborn. It has been noted that there is a tendency for nurses to act as gatekeepers, guarding access that a family has to their child (Trajkovski, Schmied, Vickers & Jackson, 2012). In a NICU practice this has the potential to become an entrenched set of behaviours because parents have not yet
established their roles in their newly expanded family. Nurses in the NICU, however are often established in their practice and may manage and control the way families interact with their babies.

Registered nurses represent by far the greatest percentage of the healthcare team in a NICU setting. Nurses have sustained and intimate contact with the families of infants throughout their stay in the NICU. At any point in time at least one nurse is directly involved in the care of each infant and their family. It is this close and sustained contact with families that makes the role of nursing in FCC pivotal to the overall delivery of care in the NICU.

My primary motivation to conduct this project was the initiation of planning for development of a new NICU space within my facility. I am currently employed in the NICU at Surrey Memorial Hospital (SMH), a large tertiary care hospital on the lower mainland east of Vancouver. Currently the NICU is a 24 bed unit, but in 2014 a new unit doubling the current capacity will be opening. Family-centred care appears to be an expected standard of care within the NICU at SMH. Official endorsement of FCC within a policy or vision statement of FH is not apparent in publicly available information. However, a Fraser Health (FH) webpage describing the new neonatal unit states: “Family-centred care will be the focus of the expanded facility and families will play an integral role in the care team.” (Fraser Health, 2011).

Construction for this new neonatal unit is well underway, with the nursery projected to open in 2014. Despite best practice recommendations to involve families in all elements of care, including environmental and structural design of facilities, up to this point there has not been any known official consultation with families in the design and construction of the NICU (Brown & Taquino, 2001; Milford, Zapalo, B & Davis, 2008). In the absence of a vision statement specific to the NICU, a group of nurses within the NICU have developed a mission statement that reflects
their values. “In NICU, we believe in providing the best possible care for our patients which supports their growth and development and which also respects the needs and involvement of the family” (B. Haan, personal communication, July 13, 2011). Though alluded to, this statement does not clearly speak of FCC, neither has it been officially endorsed by the administrative leadership of the NICU.

In the past year a renewed interest in FCC in the NICU at SMH has taken place. To a great extent, this is a result of two bedside nurses being sponsored to attend a conference sponsored by the Institute for Patient-and Family-Centered Care in Wisconsin in 2011. This interest, paired with visible progress of the structure that will house the new NICU, has created new opportunities for nurses to re-consider the role of families in the care we deliver to our patients.

To understand FCC as it relates to nurses in the NICU in Fraser Health (FH) it is necessary to understand the particular perceptions and practices of nurses working in this specific context. Although nurses working on this unit may believe themselves to be practicing from a family centered care perspective, we do not have a baseline for comparison. Furthermore, it remains unclear how one can determine whether or not a nurse’s practice is family centred. While numerous concept analyses have been undertaken, and much discussion among academics has occurred, FCC remains ill-defined. In fact, some authors believe that FCC has increasingly become more ambiguous (Mikkelsen & Frederiksen, 2011).

**Purpose of the Project**

The purpose of this project was to identify and examine instruments that have been published in the literature that have been used to assess nurses’ attitudes and perceptions about FCC in the NICU.
Specifically, this project will address the following learning goals and objectives:

1. To review current literature on FCC to identify instruments that have been developed to measure healthcare provider’s perceptions of FCC.

2. To learn about instrument development and evaluation so that I can critically analyze the instruments that are available.

3. To identify one instrument that may be useful for application in my workplace in measuring FCC.

**Theoretical Approach**

For this project, I used the theory of reasoned action (TRA) as my primary theoretical approach. This social-psychological theory was developed by Fishbein and Ajzen from research that was originally focusing on attitudes, which extended to the study of attitude as it influenced behavior and was influenced by social norms. In its simplest form, the theory of reasoned action states that a person’s attitude toward a behavior and how they think others will view them will motivate that person’s actual performance of the behavior (Ajzen & Madden, 1985). Though complexities in the theory arise when considering elements such as volitional control or social factors or norms (Manstead, 2011), the basic element of this theory is that positive attitudes toward an action prompt supportive behavior of the action.

Behavioural attitudes are an individual’s personal beliefs about a particular behavior, whether they are perceived to be positive or negative. The subjective norms are the individual’s beliefs about how they perceive others will judge the behavior. The behavioural attitudes and the subjective norms influence an individual’s behavioural intentions. If there are no interfering factors, these behavioural intentions will predict the target behavior. A perfect prediction of
behaviours cannot be predicted because there may be many contextual factors that influence a person’s willingness and ability to carry out an action (Natan, Beyil & Neta, 2009).

Figure 1: The theory of reasoned action (Natan, Beyil, & Net, 2009)

The TRA has been used in many studies to explore the relationship between nurses’ attitudes and their behaviours. Natan, Beyil & Neta (2009) used the TRA to examine nurses’ attitudes and the quality of care drug addicts received. Other researchers using the TRA have studied nurses and the use of physical restraints in elderly patients (Werner & Mendelsson, 2001), behaviour toward self-poisoning patients (McKinlay, Couston & Cowan, 2001) and care of HIV positive patients (Laschinger & Goldenberg, 2013). These studies and numerous others have demonstrated the validity of using the TRA in many contexts.

Daneman, Macaluso, and Guzzetta (2003) have identified the applicability of the TRA for healthcare workers in facilitating FCC. For example, a healthcare worker’s beliefs, attitudes and values about a particular component of FCC will influence their behaviours toward families in that area. As well, the healthcare worker’s perception of support for FCC among co-workers influences their behavioural intentions. The converse would then logically be true; the less a healthcare worker believes in FCC, the less likely that worker would be to demonstrate FCC behaviours in that area.
As previously noted, one of the limitations of the TRA in predicting behaviours is that there may be obstacles preventing a person from carrying out their behavioural intentions. In the literature, a common barrier to FCC in the NICU is typically noted to be environmental. In particular, a crowded patient care area is felt to inhibit FCC (Higman & Shaw, 2008). While these factors may be perceived by some to diminish the ability to carry out FCC, some authors dismiss this as being a barrier to FCC. Saunders et al. (2003) insist that attitudes are more important than the physical environment in the likelihood that a nurse will provide FCC.

**A Brief Summary of the Process of Instrument Development**

For this project, one of my objectives was to identify an instrument for measuring attitudes and behaviours or practices of FCC that appeared to be the most appropriate for my practice setting. To prepare myself for reviewing and assessing instruments, I undertook the additional step of briefly reviewing literature on the process of developing instruments that focused specifically on measuring social psychological constructs.

The development of a tool or instrument for research purposes is a task that involves a significant investment of time, resources, and knowledge of content experts. Prior to beginning the process of instrument development, it is essential that one has a clear understanding of the purpose and objectives of the study including operational definitions of the concepts to be measured (Benson & Clark, 1982; Streiner & Norman, 2008).

Streiner and Norman (2008) have simplified and broken down the process into three core steps: (1) searching for existing instrument, (2) constructing a new instrument, and (3) testing the instrument for validity and reliability.
Table 1: Core Steps in the Instrument Development Process (Streiner & Norman, 2008)

<table>
<thead>
<tr>
<th>Core Step</th>
<th>Brief Description</th>
</tr>
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<tbody>
<tr>
<td>1. Searching for existing instrument</td>
<td>Search the literature to see if there is an existing tool that will meet the measurement need. If there is a gap in the literature, and a tool is not available to measure the desired information, the process of instrument development begins.</td>
</tr>
<tr>
<td>2. Constructing new instrument</td>
<td>Actual construction of the instrument. This involves the construction of expert groups to contribute to the generation of specific items for the instrument, and design and refinement of the instrument.</td>
</tr>
<tr>
<td>3. Testing for reliability and validity</td>
<td>See below</td>
</tr>
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**Reliability**

The usefulness of an instrument is directly related to its reliability. Reliability is the consistency of the instrument to provide the expected results when the instrument is used on different occasions and with different samples. The primary determinants of an instrument’s reliability are established by ascertaining the 1) stability, 2) homogeneity, and 3) equivalence of an instrument (Haber, LoBiondo-Wood, Cameron & Singh, 2005). That is: Does the instrument
produce similar results on multiple uses? Do all questions on the instrument measure the same thing? Do other tools or instruments that are similar produce similar results? How does this instrument compare to well established instruments?

Various tests may be employed to determine the reliability of an instrument. The tests used to determine the reliability of an instrument are determined by the purpose of the research (Haber, LoBiondo-Wood, Cameron & Singh, 2005). Frequently Chronbach’s alpha is used to test the homogeneity of elements in an instrument (Tavakol & Dennick, 2011). A Chronbach’s alpha calculated to be from 0.70-0.95 is generally considered to be accurate, though factors such as low number of questions, or questions that are repetitive may distort the accuracy of the results (Tavako & Dennick, 2011).

**Validity**

Validity is the ability of an instrument to measure that which it purports to measure. An instrument may be reliable, and yet not valid (Loiselle & Polit, 2006). There are three main categories of validity that may be assessed when examining an instrument, these are: construct, content, and criterion validity (Streiner & Norman, 2008).

Construct validity ensures that the instrument actually measures what it is supposed to be measuring (Haber, LoBiondo-Wood, Cameron & Singh, 2005). For example, measuring parental satisfaction with the care of their hospitalized infant may not be measuring FCC, but may be measuring something else such as satisfaction with their child’s outcome.

Content validity refers to whether or not the instrument measures all areas of the concept being measured (Haber, LoBiondo-Wood, Cameron & Singh, 2005). For example, a questionnaire that only seeks information about visiting hours in a hospital ward is not measuring
FCC, but only one component of it. To measure FCC other aspects of the concept must also be measured.

To ascertain criterion validity, the results of studies using a new instrument are measured against those of another measurement tool. If there is a test that is considered the gold standard for a concept being measured, the results of both tests would be compared and criterion validity obtained (Haber, LoBiondo-Wood, Cameron & Singh, 2005). Frequently, there is no gold standard instrument. In other situations the ability of an instrument to predict an outcome that is measurable is used to determine validity. For example an instrument gathering information on particular study habits of a student may be found to have predictive validity when compared to test results that a student gets at the end of a term. The validation of an instrument is not generally accomplished through one individual study, but rather it is considered to be an ongoing process (Benson & Clark, 1982).

**Methodology**

For this project I used an integrative literature review methodology to identify and examine instruments that are available in the literature to measure nurses’ perceptions of FCC. An integrative literature review is a rigorous investigation of the current state of literature on a given topic (Torraco, 2005). Whittemore & Knafl (2005) have outlined five steps to employ when undertaking an integrative literature review. These steps are 1) problem identification, 2) literature search, 3) data evaluation, 4) data analysis, and 5) presentation. I have chosen to use the guidance provided by Whittemore & Knafl (2005) as these steps provide a structure that appears to be appropriate for use by a novice.
Application of the Steps of Integrative Review of Literature

Step 1: Problem Identification

In the first part of this paper I have reviewed the evolution, definition and implementation of FCC in the specific context of NICU practice. In order to understand and assess the FCC practices of a particular unit an instrument is required that allows evaluation of current practices, and measurement of any changes to practices and the environment.

In the NICU at SMH there is a general perception among members of the nursing team that the shift to care in single family rooms will enhance FCC. Without an assessment prior to and following the move to the new NICU model, it will be difficult to know whether or not there have been any changes in practices and improvements in FCC. Though many different healthcare workers are part of the caring team, I believe that because of the nature of their work, nurses are a major influence on the practices of FCC.

Step 2: Literature Search

I conducted a literature search in July 2013. I was searching for articles in which a researcher had used a survey instrument to measure FCC in an acute care setting. I searched four databases, including the Cumulative Index for Nursing and Allied Health (CINAHL), Health Source: Nursing/Academic Edition, Pubmed and Web of Science. I restricted my search to peer reviewed studies published in scholarly journals in English and to those studies which took place in the years following the seminal work of Shelton et al. in 1987. Initially I used the search terms family centered care, family centred care, attitude, belief, perception, practice, yielding 140 results. I repeated the search using the terms family centred care, family centered care and instrument, measurement or tool, this search yielded 111 articles. Finally, I conducted an
ancestry and descendancy search for articles that related to tools or instruments that measured nurses’ perceptions or attitudes of FCC.

**Step 3: Data Evaluation**

After hand searching and eliminating duplicate articles, or those articles not relating to my search criteria, 25 met my initial inclusion criteria. Appendix 1 contains information on the name of the study, the name of the instrument used and the focus of the study. The three remaining columns in Appendix 1 answer the questions: (1) “Is the focus of the study relevant to my project?” (2) “Is the setting relevant to the NICU?” (3) “Do the authors of the studies provide psychometric information for the instrument that they used?”

Appendix 2 shows my decision making in excluding studies. Studies that had a focus other than nurses’ practices or perceptions of FCC were excluded. Two studies were excluded because they took place on a unit that was very different from that of the NICU. Finally, studies that did not provide information on the psychometric testing of the instrument that the researcher used were excluded because I had no way of determining their reliability or validity. The resulting studies and the instruments that were used are displayed in Appendix 3.

Whittemore & Knafl (2005) include the evaluation of data as a key component in the integrative literature review. Though there is no prescribed method that will suit every integrative review, evaluating the quality of the studies being examined is important. Since my focus was the instruments that have been used, rather than the actual research results reported in the studies, I have adapted the criteria of Streiner & Norman (2008) to evaluate the quality of the studies.

Streiner & Norman (2008) maintain that it is preferable to use an existing instrument rather than designing a new one when possible. When critiquing existing instruments, these authors
provided several suggestions for a critical review. First, at a minimum, the instrument should have been reviewed by experts in the field for face and content validity. Second, assessment needs to be conducted of whether reliability for the instrument has been determined. In the case of a self-administered questionnaire, equivalence, which measures the consistency between different people conducting research using an instrument, is not generally an important factor. Instead, reliability in a self-administered questionnaire is generally concerned with internal consistency and stability. Frequently this is reported using Cronbach’s alpha and test-retest reliability.

Third, despite the fact that an instrument is reliable, there needs to be some evidence that it is also a valid measure. One of the ways to empirically test an instrument’s validity is to use another instrument, or gold standard to compare against. This causes some difficulties in the case of tool development because if there were another tool against which to compare it, there may not be a need to produce another instrument (Streiner & Norman, 2008). The solution to this dilemma according to Streiner & Norman is to use hypotheses to test construct validity. In order to do this a clear operational definition of the construct, in this case FCC must be determined.

By hypothesis testing in the context of instrument validation, Streiner & Norman are referring to the process by which it is determined that the items on a scale actually reflect the concept being studied. Streiner and Norman used the example of testing an arthritic patient’s grip on a dynamometer. Though we are not actually concerned about how well the patient can grip a dynamometer, the hypothesis being tested is that the ability to squeeze the instrument indicates strength. Therefore the hypothesis is that the greater the measurement on the dynamometer, the greater the patient’s strength. In the same way, validation of the concept FCC
is hypothesis testing. We may hypothesize, for example, that including parents in decision making for their child indicates endorsement of FCC principles.

In Appendix 4 I have examined each study using the following criteria: (1) Face or Content Validity (2) Reliability (3) and Construct validity. These criteria are subjective, as there are no explicit standards in place by which to evaluate the measurement tools of studies (Terwee et al., 2006). Each reference has been evaluated in these three specific areas. These have been rated as Terwee et al. suggested with a (+) meaning the criteria has been met, a (–) indicating that there is an intermediate amount of information and a (?) where the information is not available. The results of this are presented in Appendix 4. Using a system such as this avoids having total numeric scores for a study. This limiter is significant because providing a total numeric value may lead the reader to the conclusion that elements are equally important, when they may not be (Terwee et al., 2006). Examining each study in this way provides a clear indication of the psychometric testing that has been done for instruments that have been used more than once.

**Step 4: Data Analysis**

Data analysis is the process of reducing, displaying and comparing data (Whittemore & Knafl, 2005). Important data for the comparison of instruments is outlined by Duhn & Medves (2004). According to these authors there are three considerations for researchers and clinicians to take into account when choosing a psychometric instrument. Though these authors were choosing a tool to measure infant pain, these considerations would still be relevant for my purposes. The first is adequate reliability and the validity of the tool. Is the instrument reliably measuring that which we are intending to measure? Was the instrument developed to measure what we are wanting to measure? The second is clinical utility. Will the results be useful in the
clinical setting? The third consideration is feasibility. Is the instrument feasible for the intended use? (Duhn & Medves, 2004).

**Reliability and Validity**

Reliability for each instrument should be reported in each study. If a researcher is developing a new instrument, or using an existing instrument in a different setting, either a pilot study or reliability tests for the current sample should be performed (Haber, LoBiondo-Wood, Cameron & Singh, 2005). The results of the psychometric testing of the instruments by the authors are displayed in Appendix 5.

It is common, as is the case with the included studies, to report Cronbach’s alpha. This is a test of internal consistency. A Cronbach’s alpha of 0.7 is considered supportive of internal consistency (Haber, LoBiondo-Wood, Cameron & Singh, 2005). With the exception of the initial version of the Family Centered Care Questionnaire (FCCQ) (Bruce, & Ritchie, 1997) all the reported Cronbach’s alphas were greater than 0.7, and were therefore considered acceptable. The FCCQ had a low alpha, but revisions made to the instrument in the Family Centered Care Questionnaire-Revised (FCCQ-R) resulted in improved alpha scores.

Knowing what it is that a researcher wants to measure is fundamental. As has been previously established there are numerous conceptualizations of FCC. FCC, though it remains ill defined, continues to be the philosophical ideal for the care of children and is accepted by most healthcare practitioners. Despite the fact that there is disagreement among authors as to the definition and use of FCC, it has been used as a theoretical basis for many studies. Attempts to conduct research using FCC as a foundation must be able to clearly link theoretical constructs with the outcomes being measured.
An instrument’s validity is difficult for a reader of a research article to assess. Because of the limited amount of space allowed to an author, it is unlikely that validity will be discussed at length in a published article. Haber et al. (2005) suggests that at minimum, readers of research articles should determine whether or not the author has used the correct type of testing to ensure validity of the instrument.

Some content validity is apparent in the development of all the instruments. Two of the instruments, the FCCQ-R and the Parent Participation Attitude Scale (PPAS) relied on content validation from an earlier version of the instrument. Construct validity has been determined by factor analysis for most instruments. The FCCQ did not mention any construct validity testing, but the FCCQ-R has had factor analysis done. Sheilds &Tanner (2004) report that they had two people examine the items on their questionnaire to ensure that the items matched the constructs that they were testing. The authors concede that this is not a perfect solution, but suggest that this method does offer some evidence of validity.

**Feasibility**

Feasibility is defined as the ease with which an instrument may be used, (Duhn & Medves, 2004). Though criteria for assessing feasibility of an instrument are not readily available, the practicalities involved in using a particular instrument must weigh into its consideration. Resources such as time and money are consistently factors in conducting research. As such, the ease with which the instrument can be obtained and used is important.

All of the instruments are paper based surveys with Likert scales. The amount of time that it takes for a participant to complete a questionnaire may affect the practicality of its use. It is difficult to know the time that it will take a respondent to complete a questionnaire; however it may be assumed that self-administered questionnaires using Likert scales with fewer items will
generally take less time than those with more items. In the instruments that I am reviewing, questionnaire length varies between 24 to 107 questions.

All the paper based survey instruments appeared feasible for use in a clinical setting. Fixed response type questionnaires, such as these are frequently used because of their ease to both administer and analyze (Haber, LoBiondo-Wood, Cameron, & Singh, 2005). Ease of use is particularly desirable when time and money for the study are limited. These types of studies allow for the comparison of responses of a large number of respondents.

**Clinical Utility**

Clinical utility “...refers to the ability to use the results of the instrument in a meaningful, useful way in the clinical setting” (Duhn & Medves, 2004, p.129). An instrument is therefore useful for enhancing the practice of FCC among nurses if it is able to identify the things that strengthen and inhibit the practice of FCC in the clinical setting. As is the case for feasibility, criteria for measuring clinical utility are not readily available. Clinical utility is not referred to directly in any of the studies. One area of clinical utility that may be limited by this method is in the generation of unique responses. Respondents are not given the opportunity to provide a more in depth answer or provide an alternate perspective than that offered on the questionnaire therefore potentially decreasing the information that is provided to a researcher.

**Summary of Instruments**

Each of the instruments that I have looked at for this study has both strengths and weaknesses. Though none are perfect, it is important to choose the instrument that best meets my criteria. I will briefly summarize these 7 instruments using the criteria suggested by (Duhn & Medves, 2004).
Family Nurse Caring Belief Scale.

This instrument underwent extensive reliability and validity testing during its development. It has been used in a NICU in its testing. The instrument has 27 items making it one of the shorter tools among those I reviewed. The FNCBS is a measure of Family Sensitive Care (FSC). While there may be many slight variations among perspectives about FCC, FSC is specific in that it has a particular focus. “Family-sensitive care...refers explicitly to receptivity to the family experience...” (Meiers, et al., 2007, p. 486). This narrow focus on the nurses’ receptivity to families’ experience may limit the usefulness of the instrument for my project.

FCCQ and FCCQ-R.

The first published study using this instrument was 17 years ago. The FCCQ was revised and became the FCCQ-R. The ACCH guidelines on which the instrument is based are generally well accepted FCC guidelines. Content validity is weak because the revised instrument depends on the assessment of the original questionnaire, rather than the revised one. The FCCQ-R has been used in at least 5 published articles in that time. The item number was reduced from 55 in the original tool to 45 in the revised. It has been used in an NICU setting.

FINC-NA. The Families’ Importance in Nursing Care—Nurses’ Attitudes (FINC-NA) has had extensive psychometric testing. The developers of this instrument have offered no definition of FCC. Development and testing of the instrument occurred in Sweden. It is unknown whether or not this instrument would be applicable for use in North America. The content of the questionnaire has been derived from a panel of experts, but it is difficult to know what they might know FCC to be. The instrument was shortened to 26 questions in order to make the questionnaire more feasible to use. No other studies have used this instrument; however, it was
published only five years ago. The authors’ purpose in designing this instrument was to create a tool that was generic so would be suitable for use in a wide range of settings.

**Patient-Family-Centered Care Survey.**

A large sample size was used in the development of this instrument. No other studies have used this instrument. This study was published in 2008. Although the survey is intended to measure perceptions of the practice of FCC it is designed as a benchmarking tool for facilities to measure their improvements in FCC. The perceptions that individual nurses have about FCC in their practice would not easily be captured by this tool.

**Parent Participation Attitude Scale (PPAS).**

Content validity for this instrument is reported to have occurred in an earlier version of the tool that was developed in 1967. It is unknown how closely this content would match that of more recent ideas about FCC. The PPAS was used in an acute care paediatric setting. Sample questionnaire items given in a study using this questionnaire (Daneman, Macaluso, & Guzzetta, 2003) suggest that items may have limited usefulness in a NICU. For example: *Healthcare workers should always give the child medication, even if it is one that the child is on at home,* or *healthcare workers should give the child explanation of procedures rather than parents.* This instrument has not been used in a NICU and would require testing prior to use.

**Shields and Tanner Questionnaires.**

This instrument is made up of two questionnaires. Study samples for these tools have not been large enough for factor analysis. Limited information about validity is given. No information is given about the number of items on the questionnaires. In one study, the purpose of this tool was to be able to compare perceptions of FCC between different settings like inpatient/outpatient or acute/community care (Shields & Tanner, 2004). The second study setting
was paediatric units in general hospitals. Only small pilots have been done on this instrument. There is no indication that the questionnaires may be useful in an NICU.

**Step 5: Presentation**

The purpose of this integrative review was to examine the literature on FCC from 1987 to the present to identify instruments that have been developed to measure healthcare provider’s perceptions of FCC and to identify an instrument that may be useful for application in my workplace. A recent search on CINAHL with the term “family centered care” generated over 4,000 results. Clearly this is a topic of interest to many. Streiner & Norman (2008) emphasize that the process of developing a reliable and valid instrument is both labour intensive and time consuming. Therefore it is prudent to search for and use a previously developed instrument when available.

It is interesting to note that only three instruments were used more than a single time in the published literature that I was able to retrieve. The Family Centered Care Questionnaire (FCCCQ) and its revised version, the Family Centered Care Questionnaire-Revised (FCCQ-R) were used a total of six times. The Parent Participation Attitude Scale (PPAS) and the Tanner and Shields questionnaires were used twice. Explanations for the apparent single usage only for most of these instruments may be: 1) the instruments have been used, but not in published studies 2) articles using the instruments may not have met my search criteria, for example used in rehabilitation settings rather than acute care, and 3) researchers may not be satisfied that other instruments will be suitable for their purpose and so have developed their own.

Most of the instruments retrieved are still in the development and testing phase. This would seem logical given that few of the instruments have been used in more than one study. Use in
multiple settings along with appropriate psychometric testing would strengthen the reliability and validity of these instruments.

The retrieved studies of FCC have included the perspectives of many different healthcare practitioners including: nurses, nursing assistants, respiratory therapists, medical residents, physicians, other allied staff, volunteers, and administrative staff (Shields et al., 2003; Daneman, 2003). Some studies have looked exclusively at nurses, and some have looked at other members of the healthcare team in combination with the nurses. In most acute care settings nurses comprise a significant proportion of the healthcare team, and have the greatest amount and the closest level of contact with families. Because of this, it can be expected that the perceptions that nurses have of FCC will be extremely influential in determining how FCC is carried out in a particular setting. None of the studies exclude nurses from their sample.

One of the difficulties in finding an appropriate instrument to measure perceptions of FCC is the differences that researchers have in their underlying beliefs about FCC. The Family Nurse Caring Belief Scale (FNCBS) was designed to measure the family-nurse interaction (Meiers, et al., 2007). It may be argued that the FNCBS is not really a measurement of FCC. FCC is not mentioned by Meiers (2007) in her article, but instead family-sensitive care is the concept term that is used to frame the research.

*Family sensitive care* clarifies the philosophy of *family centred care* and refers explicitly to receptivity to family experience while utilizing and ordering these perceptions in order to be responsive to emerging family needs. (Tomlinson, Thomlinson, Peden-McAlpine & Kirschbaum, 2002, p. 162)

Different terminology is used to describe FCC in the retrieved studies. Families’ importance (Benzein, Johansson, Årestedt, Berg, & Saveman, 2008), and participation (Gill,
are some of the terms used. Though it can be argued that these terms represent only a part of FCC, it is less important what terms are used versus the way these terms are understood to the researcher and the reader.

It is essential that the researcher understands the definition of FCC that they are investigating, and that this conceptualization is represented by the instrument that is used. While many of the studies use instruments that define FCC according to the ACCH principles or the IPFCC some of the studies have not made clear which conceptualization of FCC the instruments that they are using are testing.

During the past 10 years, six authors have used the family-centred care questionnaire (FCCQ) developed by Beth Bruce in 1992 (Letourneau & Elliot, 1996). This questionnaire is based on the principles outlined by the ACCH. These eight elements are:

1. Recognizing that the family is the constant in a child’s life, whereas service systems and personnel within those systems fluctuate.

2. Facilitating parent/professional collaboration at all levels of healthcare.

3. Recognizing family strengths and individuality, and respecting different methods of coping.

4. Sharing unbiased and complete information with parents about their child’s care on an ongoing basis in an appropriate and supportive manner.

5. Encouraging and facilitating parent-to-parent support.

6. Understanding and incorporating the developmental needs of infants, children, adolescents and their families into healthcare systems.

7. Implementing appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families.
8. Assuring that the design of the healthcare delivery system is flexible, accessible and responsive to family needs. (Shelton, Jeppson, & Johnson, 1987, 1)

The FCCQ originated in work that Beth Bruce did in 1992 for her master’s thesis (Letourneau & Elliot, 1996). The original FCCQ had 55 items. The FCCQ-R has since been reduced to 45 items. The FCCQ-R has been used in both the NICU and paediatric units in various areas of Canada, as well as one study that took place in Ireland. The FCCQ-R measures the perceptions of a nurse comparing what that nurse believes should be FCC practice and what he or she believes current practice actually is.

Franck and Callery (2004) suggest substruction as a method by which the abstract ideas such as FCC can be tested. Substruction is a process used to link abstract ideas to measurable outcomes. In this process, ideas that are more highly theoretical are logically traced to more concrete levels in steps. Abstract ideas, such as FCC that are very abstract are made more concrete by the delineation of constructs. Constructs, still being abstract, are further reduced to concepts which fall under individual constructs. In order to further decrease the level of abstraction of concepts, empirical indicators are derived that provide means for measurement. A researcher must be clear that the indicators being measured fit the researcher’s understanding of FCC.

For example (Figure 2), one of the ACCH guidelines of FCC is that Family is the Constant. This construct is then broken down into concepts. Encouragement of family visitation is a concept that can then be measured using empirical indicators. For example, questions regarding visiting hours or amenities for visitors may be used as empirical indicators to measure the encouragement of family visitation. In this way the abstract idea of FCC can be made more
concrete. Each of the components of FCC can be broken down in this way to provide a more complete picture of FCC.

**Figure 2. Substruction of FCC**

In each of the studies that I have examined, the researchers have used instruments that have reduced the idea of FCC to measureable indicators. As a reader of these studies it is not always possible to determine how the link between the concept and the measureable indicator has been made. The amount of space allotted in a publication for the write up of a research project does not always allow the author to clearly show the link between the construct and each of its empirical indicators. It is important to know that the author has considered the ways that the items on a questionnaire align with the conceptualization of FCC being tested.

The fact that there are no standardized instruments to measure perceptions of FCC suggests that there has not yet been a tool developed that adequately meets the needs of researchers to investigate this theory completely. This is not surprising given the differing understandings of FCC itself. Despite the numerous definitions of and approaches to FCC, most conceptualizations of FCC include three main components. These are: (1) empowerment of the child and family,
acknowledgement of the importance of the family to a child’s well being, and (3) collaboration between healthcare providers and families (Franck & Callery, 2004).

In this next section I will present further analysis of the instruments in relation to key considerations that will assist me in determining which instrument will be the most appropriate for use in my workplace. These considerations include reliability and validity, clinical utility, and feasibility (Duhn & Medves, 2004).

My Process of Identifying an Instrument for my Workplace Context

As has been discovered by others, I have determined that there is no instrument currently available that clearly meets all the needs of the study that I would like to conduct. Streiner & Norman (2008) caution against exaggerating the flaws in existing instruments and playing down the work that is involved in creating a new one. With this in mind I acknowledge that time and financial resources will not allow me to develop an instrument that improves upon the available instruments.

After conducting this review, I have determined that the FCCQ–R is the most suitable instrument for use in my practice setting. This tool met my initial criteria of an instrument to measure nurses’ practices and perceptions of FCC. There has been very limited repeated use of valid and reliable instruments measuring nurses’ perceptions of FCC in the literature published up until this time.

It appears that limited reliability and validity testing has occurred with this instrument, even when the instrument was used in a different setting than had been originally intended. Ideally any changes to the instrument would be accompanied by reliability and validity testing prior to carrying out a study. In addition, psychometric testing should occur prior to the tool’s use in different settings, particularly in the NICU.
Initially this instrument was developed for use in paediatrics, but has been used in a NICU by Petersen, et al. (2004). Despite its prior use in a NICU setting there are seven questions on the FCCQ that are not directly applicable to the nursery. Unfortunately, the authors have not addressed this issue in their article. The FCCQ frequently refers to child and family. At times this is problematic for use in the NICU. This is particularly the case when referring to children’s actions which are developmentally beyond the capacities of an infant. In this case, wording would need to be changed to reflect the age and developmental stage of infants in the NICU and the fact that generally the family is acting on behalf of that infant.

In addition, some minor wording changes need to be made to clarify items. For instance, instead of using the word child, it may sound more appropriate to use the word baby, as our patients are most commonly referred to. This minor level of wording change would not alter the original intent or structure of the tool.

Bruce and Ritchie (1997) developed the FCCQ by taking the concepts of FCC identified by Shelton et al. (1987) and operationalizing them in this instrument. By doing so they have been able to itemize the highly abstract idea of FCC and have provided a method by which to measure it. Though the FCCQ is not without flaws, it appears to be the most suitable instrument available at this time to meet my needs as I develop a methodology to study the impact of a new single room environment on the ability of NICU nurses to provide FCC in my institution.

**Significance to Nursing**

I believe that FCC is not a “nice” thing to do. I believe that it is an essential part of good healthcare in the NICU. Members of the NICU team in Surrey are in an interesting position in that they will be experiencing significant environmental and practice changes in the next few years. As the healthcare team in the SHM NICU strives to become increasingly more family
centred it would be beneficial to be able to explore nurses’ attitudes about FCC and any changes that are occurring over time. Currently the nursery is composed of open rooms with many infants sharing the same room. The new nursery will have individual rooms for each infant, or, in the case of twins, each pair of infants. Among other purposes, the single family room nursery is intended to promote FCC. Space will be provided for family to be with their infants at all times.

Despite the change to a SFR nursery, there are still many challenges ahead. Of particular significance in Surrey is the multicultural aspect to our community and our families. Though efforts are being made within the health region to respect this cultural diversity (Fraser Health, 2012), and the healthcare team increasingly reflects the cultural diversity of our community, cultural differences are not always recognized or accepted. So far there have not been instruments developed for use that address the influence of culture on our practice of FCC. I acknowledge this limitation in the use of the FCCQ-R.

Though individual rooms will likely make it physically easier to have parents and family involved in the care of their child than at present, it remains to be seen if this change will translate to improved FCC. It is clear from the precepts of FCC laid out by Shelton, Jeppson & Johnson (1987) that mere family presence does not constitute the whole of FCC. If nurses believe that FCC is important for infants in the NICU, philosophical beliefs and everyday practice must be moving toward alignment. New ideas are continually being advanced.

At present there is a study underway in Canada which promotes the idea of family integrated care in the NICU setting. The program supports families meeting specific criteria who are able to commit to spending at least eight hours a day with their infant in the NICU. These families have been able to participate as team members in their child’s NICU care in ways that
have not previously been a standard of care in Canada. Results of this project look promising so far in regards to family satisfaction with those who are able to participate (Bracht, Oleary, Lee & Obrien, 2013).

Just as there have been many changes that have taken in place in healthcare in the past, particularly in neonatology, there will continue to be changes in the future. The theory of reasoned action serves to remind us that the way that we practice is shaped by our beliefs, the influence of those around us, and the context for care. The act of changing the environment or practices will not necessarily positively impact FCC, if individual nurses, and unit culture do not hold beliefs that support FCC. Effort needs to be made to recognize the underlying attitudes of nurses in the NICU and support the understanding of the benefit that FCC brings to our NICU patients/families. Nurses’ beliefs in the value of FCC along with cultural support and organizational resources should lead to nursing care practices that encourage empowerment of the parents and family, recognition of the importance of the family to the newborn’s well being and improved collaboration between nurses and families.
References


### Appendix 1-Retrieved Articles

<table>
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<tr>
<th>*1</th>
<th>Article</th>
<th>Instrument</th>
<th>Focus</th>
<th>Relevant Setting</th>
<th>Relevant Psychometric Information Included</th>
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<tbody>
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<td></td>
<td>Asai, H. (2011). <em>Predictors of nurses' family-centered care practices in the neonatal intensive care unit</em></td>
<td>Measure of processes of care for service providers (MPOC-SP) Measure of beliefs about participation in family-centered service (MBP-FCS)</td>
<td>Practices and beliefs of neonatal nurses</td>
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<td>Bruce, B. &amp; Ritchie, J. (1997). <em>Nurses' practices and perceptions of family-centered care</em></td>
<td>Family centered care questionnaire (FCCQ)</td>
<td>Nurses’ perceptions and practices in paediatric hospital</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<td>Bruce, B., Letourneau, N., Ritchie, J., Larocque, S., Dennis, C., &amp; Elliot, M. (2002). <em>A multisite study of health professionals' perceptions and practices of family-centered care</em></td>
<td>Family centered care questionnaire-revised (FCCQ-R)</td>
<td>Nurses’ perceptions and practices in paediatric hospital</td>
<td>Yes</td>
<td>Yes</td>
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<td>Carmen, S., Teal, S., &amp; Guzzetta, C. E. (2008). <em>Development, testing, and national evaluation of a pediatric patient-family-centered care benchmarking survey</em></td>
<td>Patient-family centered care survey</td>
<td>Perceptions of families, leadership and staff in a paediatric healthcare centre</td>
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<td>Curley, M. A., Hunsberger, M., &amp; Harris, S. K. (2013). <em>Psychometric Evaluation of the Family-Centered Care Scale for Pediatric Acute Care Nursing</em></td>
<td>Family-centered care scale</td>
<td>Perceptions of parents in paediatric hospital</td>
<td>No</td>
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<td>Daneman, S. Macaluso, J. &amp; Guzzetta, C. (2003). Healthcare providers' attitudes toward parent participation in the care of the hospitalized child</td>
<td>Parent participation attitude scale (PPAS)</td>
<td>Paediatric healthcare providers attitudes</td>
<td>Yes</td>
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<td>13</td>
<td>Eckle, N., &amp; MacLean, S. L. (2001). Assessment of family-centered care policies and practices for pediatric patients in nine US emergency departments</td>
<td>Self-assessment inventory of family-centered practices</td>
<td>Assessment of FCC practices of staff for paediatric patients in emergency</td>
<td>Yes</td>
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<td>Gill, K. M. (1993). Health professionals' attitudes toward parent participation in hospitalized children's care</td>
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<td>Hughes, M. (2007). Parents' and nurses' attitudes to family-centred care: An Irish perspective</td>
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<td>Parents’ and nurses’ attitudes in a paediatric unit</td>
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<td>Jacono, J., Hicks, G., Antonioni, C., O’Brien, K., &amp; Rasi, M. (1990). Comparison of perceived needs of family members between registered nurses and family members of critically ill patients in intensive care and neonatal intensive care units</td>
<td>Norris and Grove questionnaire</td>
<td>Perceptions of nurses and family in NICU and ICU</td>
<td>Yes</td>
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<td>Klassen, A. F., Dix, D., Cano, S. J., Papsdorf, M., Sung, L., &amp; Klaassen, R. J. (2009). Evaluating family-centred service in paediatric oncology with the measure of processes of care (MPOC-20)</td>
<td>MPOC-20</td>
<td>Parental perception on paediatric unit</td>
<td>No</td>
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<td>Letourneau, N., &amp; Elliot, R. (1996). Pediatric health care professionals' perceptions and practices of family-centered care</td>
<td>FCCQ-R</td>
<td>Practices and perceptions of healthcare professionals in a paediatric hospital</td>
<td>Yes</td>
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<td>Neal, A., Frost, M., Kuhn, J., Green, A., Gance-Cleveland, B., &amp; Kersten, R. (2007). Family centered care within an infant-toddler unit</td>
<td>Institute of Family Centered Care survey</td>
<td>Attitudes of parents and nurses in a paediatric unit</td>
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<td>Petersen, M., Cohen, J., &amp; Parsons, V. (2004). &lt;br&gt;Family-centered care: Do we practice what we preach?</td>
<td>FCCQ-R</td>
<td>Nurses’ perceptions and practices in NICU, paediatrics, PICU</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>Saunders, R., Abraham, M., Crosby, M., Thomas, K., &amp; Edwards, W. (2003). &lt;br&gt;Evaluation and development of potentially better practices for improving family-centered care in neonatal intensive care units</td>
<td>NICU Care Provider Questionnaire</td>
<td>Beliefs and practices of staff of NICU</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Shields, L., &amp; Tanner, A. (2004). &lt;br&gt;Pilot study of a tool to investigate perceptions of family-centered care in different care settings</td>
<td>Shields and Tanner</td>
<td>Comparison of parents’ and staff’s perception in outpatient, inpatient, hospital, community, public, private, acute, chronic, short term hospitalization, and long term hospitalization</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

*Studies meeting inclusion and exclusion criteria
Appendix 2 Decision Flowchart

25 retrieved studies → 5 studies with focus not relevant to my project removed → 20 studies

20 studies → 2 studies with a setting in adult ICU and paediatric emergency removed → 18 studies

18 studies → 5 studies not indicating psychometric testing of the instrument removed → 13 studies

13 studies → 7 instruments
## Appendix 3-Table of the Instruments Used in Included Studies

<table>
<thead>
<tr>
<th>Instrument Name</th>
<th>Number of times used in studies retrieved</th>
<th>Contexts</th>
<th>Sample sizes</th>
<th>Conceptualization of FCC</th>
<th>Number of items</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) FNCBS</td>
<td>1</td>
<td>ICU NICU PICU USA</td>
<td>163</td>
<td>Tomlinson, Thomlinson, et al., 2002 definition</td>
<td>27 items</td>
</tr>
<tr>
<td>2) FCCQ</td>
<td>1</td>
<td>Paediatrics NICU</td>
<td>124 62</td>
<td>ACCH guidelines</td>
<td>55 items</td>
</tr>
<tr>
<td>Bruce, B. &amp; Ritchie, J. (1997)</td>
<td></td>
<td></td>
<td></td>
<td>5 point Likert</td>
<td></td>
</tr>
<tr>
<td>3) FCCQ-R</td>
<td>5</td>
<td>NICU Paediatrics Canada Ireland</td>
<td>483 250</td>
<td>ACCH guidelines</td>
<td>45 item</td>
</tr>
<tr>
<td>Murphy, M., &amp; Feely, G. (2007)</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4) FINC-NA</td>
<td>1</td>
<td>Sweden</td>
<td>634</td>
<td>None stated Items derived from content experts</td>
<td>26 item</td>
</tr>
<tr>
<td>5) Patient-family-centered care survey</td>
<td>1</td>
<td>Paediatric hospitals USA</td>
<td>1703</td>
<td>Institute for Family-Centered Care</td>
<td>107 items</td>
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<tr>
<td>Carmen, S., Teal, S., &amp; Guzzetta, C. E. (2008)</td>
<td></td>
<td></td>
<td></td>
<td>4 point Likert</td>
<td></td>
</tr>
<tr>
<td>Instrument Name</td>
<td>Number of times used in studies retrieved</td>
<td>Contexts</td>
<td>Sample sizes</td>
<td>Conceptualization of FCC</td>
<td>Number of items</td>
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<td>-----------------</td>
<td>------------------------------------------</td>
<td>----------</td>
<td>--------------</td>
<td>--------------------------</td>
<td>-----------------</td>
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<tr>
<td>6) PPAS</td>
<td></td>
<td>2</td>
<td>Paediatric hospital US Members of ACCH Canada and USA 256 651</td>
<td>Supports integrity of family and individualizes care</td>
<td>24 item 5 point Likert</td>
</tr>
<tr>
<td>7) Shields and Tanner questionnaires</td>
<td></td>
<td>2</td>
<td>Hospital Community Australia (pilot) 60 (pilot) 50</td>
<td>Concepts: respect, collaboration, support, decision making, communication</td>
<td>Not stated</td>
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</tbody>
</table>
## Appendix 4. Reliability and Validity

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Face or Content Validity</th>
<th>Reliability</th>
<th>Construct Validity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) FNCBS</td>
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<td>+</td>
<td>+</td>
</tr>
<tr>
<td>2) FCCQ</td>
<td>+</td>
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<td>-</td>
</tr>
<tr>
<td>Bruce, B. &amp; Ritchie, J. (1997)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3) FCCQ-R</td>
<td>+</td>
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<tr>
<td>Caty, S., Larocque, S., &amp; Koren, I. (2000)</td>
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<td>-</td>
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<tr>
<td>Letourneau, N., &amp; Elliot, R. (1996)</td>
<td>-</td>
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<td>-</td>
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<tr>
<td>Murphy, M., &amp; Feely, G. (2007)</td>
<td>+</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Petersen, M., Cohen, J., &amp; Parsons, V. (2004)</td>
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<td>-</td>
</tr>
<tr>
<td>4) FINC-NA</td>
<td>+</td>
<td>+</td>
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<tr>
<td>5) Patient-family-centered care survey</td>
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<td>+</td>
</tr>
<tr>
<td>6) PPAS</td>
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<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Gill, K. M. (1993)</td>
<td>-</td>
<td>-</td>
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<tr>
<td>7) Shields and Tanner questionnaires</td>
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<td>+</td>
<td>-</td>
</tr>
<tr>
<td>Aggarwal S., Chadha P., Kalia S., Richardson S., Winterbottom L., Shields L. (2009)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Face and Content Validity</td>
<td>Reliability</td>
<td>Construct Validity</td>
<td></td>
</tr>
<tr>
<td>--------------------------</td>
<td>-------------</td>
<td>--------------------</td>
<td></td>
</tr>
<tr>
<td>Sources specified +</td>
<td>Appropriate reliability measures specified +</td>
<td>Instrument congruent with working definition of FCC +</td>
<td></td>
</tr>
<tr>
<td>Done but sources not specified or not performed for this study -</td>
<td>Measures from a previous study quoted, but not performed for this study -</td>
<td>Working definition of FCC but no construct validation -</td>
<td></td>
</tr>
<tr>
<td>Information not available ?</td>
<td>Information not available ?</td>
<td>Information not available ?</td>
<td></td>
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</table>
# Appendix 5. Psychometric Testing

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Reliability</th>
<th>Validity</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1) FNCBS</strong>&lt;br&gt;Meiers, S., Tomlinson, P., &amp; Peden-McAlpine, C. (2007)&lt;br&gt;Cronbach’s alpha = .81&lt;br&gt;Guttman split-half = .78&lt;br&gt;Content validity: panel of experts&lt;br&gt;Concurrent validity: Pearson’s r = .57 (p&lt;0.1) when compared to the Caring Behaviors Inventory&lt;br&gt;Construct validity: factor analysis</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>2) FCCQ</strong>&lt;br&gt;Bruce, B. &amp; Ritchie, J. (1997)&lt;br&gt;Cronbach’s alpha = 0.5-0.8 for subscales and 0.9 for total scales&lt;br&gt;Test-retest = 0.6-0.8&lt;br&gt;Content validity: panel of experts</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>4) FINC-NA</strong>&lt;br&gt;Benzein, E., Johansson, P., Årestedt, K. F., Berg, A., &amp; Säve-Richter, B. I. (2008)&lt;br&gt;Cronbach’s alpha = 0.88&lt;br&gt;Content validity: panel of experts&lt;br&gt;Construct validity: factor analysis</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>5) Patient-family-centered care survey</strong>&lt;br&gt;Carmen, S., Teal, S., &amp; Guzzetta, C. E. (2008)&lt;br&gt;Cronbach’s alpha = 0.76 – 0.94&lt;br&gt;Construct validity: factor analysis</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>7) Shields and Tanner questionnaires</strong>&lt;br&gt;Aggarwal S., Chadha P., Kalia S., Richardson S., Winterbottom&lt;br&gt;Modified test-retest = &gt;0.9&lt;br&gt;Cronbach’s alpha = 0.72-0.79&lt;br&gt;Content validity: expert panel&lt;br&gt;Criterion validity: unspecified comparison to other measures&lt;br&gt;Construct validity: two</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Instrument</td>
<td>Reliability</td>
<td>Validity</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>-------------</td>
<td>---------------------------------------</td>
</tr>
<tr>
<td>L., Shields L. (2009)</td>
<td></td>
<td>people examine the logical sequence</td>
</tr>
</tbody>
</table>