# Toward developing consensus on family-centred care: an international descriptive study and discussion

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## Abstract

Nurses around the world have described family-centred care in various ways. With limited evidence regarding its implementation and with dissent among professionals regarding outcomes that are amorphously defined across age groups, systems and global settings, a group of children's nursing experts from around the world collaborated to seek clarification of the terms, deconstruct the elements in the model and describe empirically a consensus of values toward operationally defining family-centred care. A modified Delphi method was used drawing on expert opinions of participants from eight countries to develop a contemporary and internationally agreed list of 27 statements (descriptors of FCC) that could form the foundation for a measure for future empirical psychometric study of family-centred care across settings and countries. Results indicated that even among FCC experts, understandings of FCC differ and that this may account for some of the confusion and conceptual disagreement. Recommendations were identified to underpin the development of a clearer vision of FCC.

## Background

Family-centred care (FCC) in some form or another is widely taught, promoted, used but questionably implemented at best (Carter, 2008). Almost every nurse caring for children and their families will have an opinion about it and many research papers have concluded that it is not working as well as it should and that more research/effort/intervention/reflection needs to be done to improve the implementation of family-centred care. Many organisations provide a formal description and definition of FCC (The American Academy of Pediatrics, 2012; The Institute for Patient- and Family-Centered Care, 2017; US Department of Human Services, 2017; Maternal and Child Health Bureau, 2005; Agency for Healthcare Research and Quality, 2017), but as more studies about FCC have emerged, the more disparate the cumulative understanding of the model has become. Another, and related, challenge to FCC practice is the long-standing and on-going debate among researchers and health professionals surrounding a definition of FCC as well as the

implications of, and requirements for, FCC in practice, and differences of FCC understanding across cultures (Al-Motlaq & Shields, 2017).

All definitions of FCC generally circle around the same ideal of placing the child and family at the centre of care. The Institute for Patient- and Family-Centered Care (2017) defined patient- and family-centred care as *"…an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families*". The American Academy of Pediatrics (2012) stated that FCC is a necessary component of clinical decision-making and that families should collaborate with healthcare professionals in all aspects of care, allowing them to participate at the level they choose. Others (Smith, Coleman and Bradshaw, 2002, p.22) describe it as "*the professional support of the child and family through a process of involvement, participation, and partnership underpinned by empowerment and negotiation*". The American Academy of Pediatrics (2012) outlined the main principles of FCC and linked it to improved health outcomes. The updated version of resources provided by the Institute for Patient- and Family-Centered Care (2017) offers guidance on advancing the practice of FCC care by direct engagement with patients and families in all aspects of their health care. It also asserts that studies increasingly show that when staff, patients and families work in partnership, the quality and safety of health care rises, costs decrease, and satisfaction improves (Bertakis, & Azari, 2011; Stewart et al., 2000; Sweeney, Halpert, & Waranoff, 2007). The literature is replete with inconsistent claims about FCC and what it can offer children, their families and health services. Others have assessed FCC using tools such as the Measure of Processes of Care (MPOC) developed by King, Rosenbaum and Kin (1997). Medicine, in particular, has used these tools. However, tools such as MPOC were developed for use in disability services and measure parents' perceptions of the extent to which services are family-centred and do not cover wider aspects of family centred care (Shields et al., 2012).

The concept of FCC is often poorly characterised and imprecisely described and the rigor of the research that has studied the concept has been variable (Backman et al., 2017; Kuo et al., 2012; Sidani & Fox, 2014; Shields, 2011). Without conceptual clarity, many of the claims that have been made about the benefits, or otherwise, of FCC lack a solid foundation (Carter, 2008; Uniacke, Kayali-Browne, Shields 2018). Family-centred care is considered a multidimensional and complex concept (Allen & Petr, 1998). We believe that the concept spans more than one theory or definition. Possibly, the best way to describe the model might be by exploring its detailed components. The level of confusion and misunderstanding in the literature was the starting point for our decision to re-examine the FCC model. Early virtual discussions with key international experts in children's nursing led to the impetus for a study to move the field forward.

The main aim of this study was to develop a contemporary and internationally agreed list of items (descriptors of FCC) that could form the foundation for a measure for future empirical psychometric study of FCC across settings and countries. A secondary aim was to develop a list of recommendations to underpin future thinking about FCC.

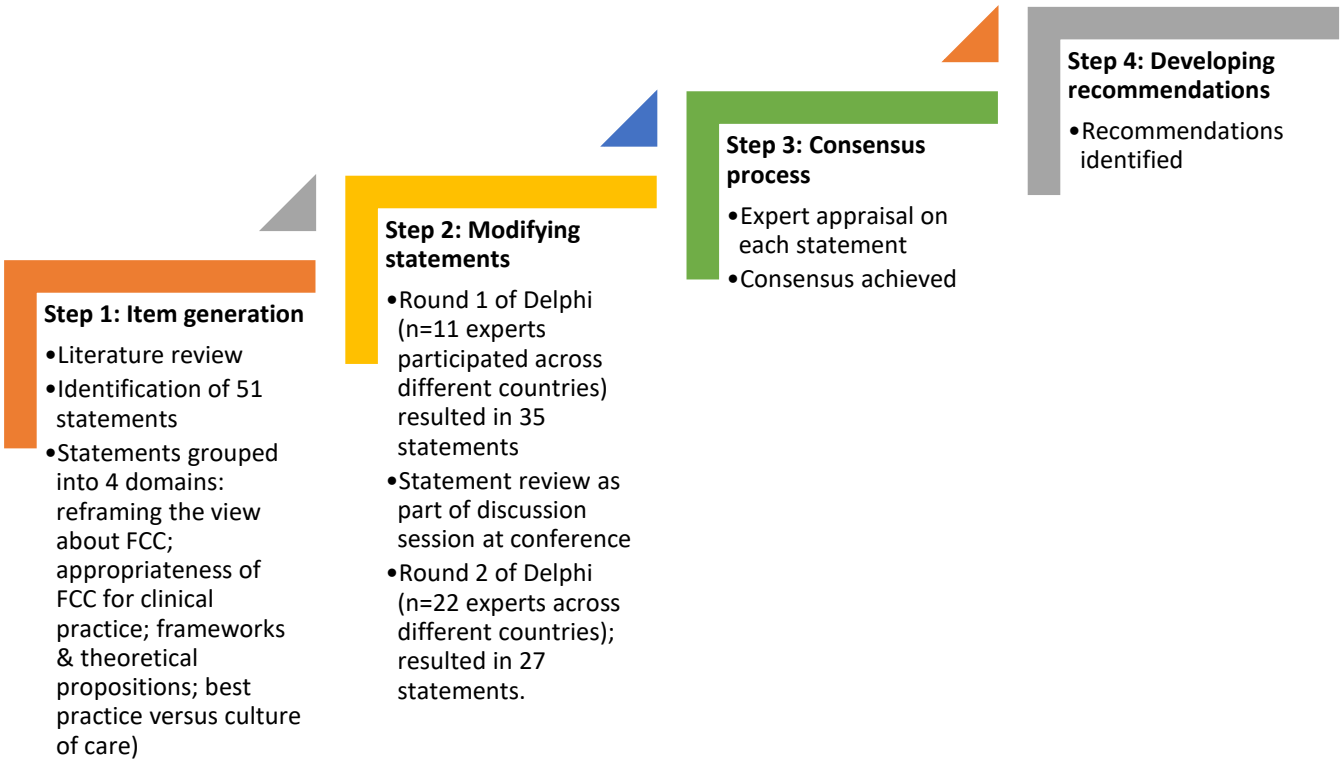
## Methods

The study used consensus methodology by employing a modified Delphi technique (Polit & Beck, 2017) to explore and to establish agreement on the description of FCC and its constituent characteristics. The Hashemite University IRB committee in Jordan gave confirmation that ethics approval was not necessary for this study.

A four-step approach was used: (1) item generation: generating of statements based on an extensive literature review; (2) modifying and refining statements: supported by assistance from a panel of experts; (3) consensus process: obtaining expert appraisal of each statement by conducting a voting

session using a rating scale; and (4) developing recommendations regarding FCC, clinical practice and future research priorities based on those statements with the highest consensus (Figure 1).

**Figure 1: Consensus Process**




### *Step 1: Item generation*

An initial comprehensive literature search on FCC related studies was undertaken with the following key search terms (family centered care, child health, models of service delivery) using MEDLINE and CINAHL databases and Google Scholar search engine. A definition or description of FCC following hyperlinks and references was systematically sought. Studies included were from the year 2000 onward. They had to have used rigorous methods as defined by the Cochrane handbook (Higgins &

Green, 2011), presented sound interpretations and be relevant to the implementation of FCC, children and families. Papers from any discipline were accepted. Duplicates were removed. The included articles were used to formulate statements which were edited and refined until a final list of 51 statements was created that reflected the range of description and characteristics of FCC published in the literature. These 51 statements were grouped into four domains: reframing the view about FCC; the appropriateness of FCC for clinical practice; frameworks and theoretical propositions; and best practice versus culture of care.

### *Step 2: Modifying and narrowing down the statements*

This process occurred through three stages: two rounds of a Delphi survey and one discussion group and reflects the contributions of nurses working in Australia, England, Iceland, Ireland, Jordan, New Zealand, Sweden, and the United States of America.

In the first round of the Delphi survey the pooled statements were emailed to a core of 18 experts from an international FCC network, with the option for those core members to forward it onto other experts. The survey asked for their comments and assessments of the degree to which they agreed or disagreed with each statement. Eleven experts participated and their responses were compiled into a single spreadsheet and compared and contrasted. They also provided comments, modified the wording of items, argued for or against the statements and offered suggestions. Each comment was carefully assessed. Statements were retained, modified and/or removed based on the experts' responses. The 51 statements were reduced to 35 statements which reflected the highest agreement, as per the modified Delphi technique described by Linstone and Turhoff (1975), which was used to reach consensus on statements. This is a well-recognised and validated way to reach consensus on debateable issues, in particular when clinical evidence is lacking.

In an effort to extend the discussion of these 35 statements and to generate further clarity about the wording of the statements, potential duplication/redundancy and to identify if any relevant items/areas had been missed, a discussion session was undertaken at the 28th International Nursing Research Congress held in Dublin, Ireland on the 30th of July 2017. Notes of the discussion were documented and provided the basis for further refinement of the statements by the researchers which were then sent out as Round 2 of the survey to the original 18 experts who again were able to forward it to others; 22 responses were received. At the end of Round 2, a final list of 27 clearly articulated, robust statements with a high level of agreement was identified.

### *Step 3: Consensus process (voting phase)*

Items were placed on a rating scale for experts to vote (1 to 7 points). Items with score of 6 or higher were deemed to have strong consensus; those with a score of 5 were deemed to reflect 'moderate' consensus and those that scored 4 or lower were considered to have weak consensus. The voting process excluded any expert with any perceived conflict of interest. The voting process generated statements with high consensus and these were used as the basis for recommendations regarding FCC, clinical practice and future research priorities.

## Results

The tables below present the 27 statements generated from steps 1 and 2. Each statement is presented along with the scores from step 3. Table 1 presents three statements with relatively weak agreement (mean score <5, median score 5) which suggests that these items may not be useful for inclusion in a FCC measure. However, it is important to consider the variability of experts' scores demonstrated by large standard deviations.

### Table 1: Statements with weaker agreement (mean score lower than 5 – median 5)

| Statement | Mean | SD | Median | Mode |
|---|---|---|---|---|
| 1: It's not easy to say FCC has no actual evidence hence must be substituted. Although it is not perfectly practiced worldwide, some reports documented the benefits of practicing FCC in the hospital | 4.86 | 1.773 | 5.00 | 5 |

| | | | | |
|---|---|---|---|---|
| setting. Practicing “non-FCC” wouldn't look good in a children’s setting. It is far better than any alternative available. | | | | |
| 4: FCC is culturally sensitive which builds a trusting environment through supporting relationships that value and recognise the importance of family traditions, beliefs, and management styles as health care providers collaborate with family members in providing individualised care. | 4.86 | 1.952 | 5.00 | 5 |
| 26: FCC is a standard of care delivery and not reliant on policies and procedures, so it can always be incorporated into the health care setting, no matter the hospital policy. FCC is possible within the framework of any healthcare that exists | 4.57 | 1.134 | 5.00 | 5 |

Table 2 presents those with moderate agreement and demonstrates the variability in the scoring amongst the experts. These statements were mostly concerned with the applicability of FCC where experts differed in their recognition of what the FCC application actually entails.

**Table 2: Statements with moderate agreement (subject to criticism) – mean score between 5 and 6 (median 5, 6 or 7)**

| Statement | Mean | SD | Median | Mode |
|---|---|---|---|---|
| 2: Over time and as the profession matured, nursing education and practice expanded and shifted to more family-centered care and had more of a family centered focus, at least theoretically. | 5.86 | 1.069 | 6.00 | 6 |
| 10: FCC acknowledges families need to be involved in health team decision making and care of their child but this involvement is deferred to experts when parents are not capable of being decision makers. | 5.57 | 1.272 | 6.00 | 4 |
| 13: Parents shouldn’t have to negotiate in true FCC. Great FCC should allow families and staff to discuss collaboration, and can happen in acute as well as long-term care and starts from the moment of admission to after discharge. | 5.43 | 2.149 | 6.00 | 7 |
| 17: Challenges faces nurses include: balancing technical needs of their patients and practicing holistic family-centered care. | 5.71 | .488 | 6.00 | 6 |
| 22: The debate surrounds FCC exists in its interpretation and applicability in health services. Therefore, we will see it change, thrive and adapt according to the circumstances while adhering to key important principles. | 5.71 | 1.113 | 6.00 | 5 |
| 24: The main problem in FCC application is about the health professionals and policies. To make FCC work commitment by all health professionals, managers of health services and policy makers are needed. | 5.86 | 1.574 | 7.00 | 7 |
| 15: FCC is practiced in PICU, NICU and ICU areas but critical care needs are different or more importantly the timing of these needs are different. | 5.00 | 1.732 | 5.00 | 5 |

Table 3 presents those statements with strong agreement. Experts mostly agreed with the statements that demonstrated the theoretical grounding of FCC, or proposed solutions for its best application. These items may become applicable in the development of a measure that is not limited in applicability across settings.

### Table 3: Statements with strong agreement (approved consensus) – SD less than 1 with a mean of 6 or more

| Statement | Mean | SD | Median | Mode |
|---|---|---|---|---|
| 3: Theoretically, FCC involves an active choice of participation/engagement/involvement between child/young person, families and health care professionals. | 6.00 | 1.000 | 6.00 | 6 |
| 5: FCC recognises the strengths, limitations and needs of families and patients hence encourages parents to choose whether or not to have an active role in supported care giving; a choice established with collaboration. | 6.00 | .816 | 6.00 | 6 |
| 6: Nurses may find barriers in their practice settings, organisational environment, and their individual beliefs, attitudes and philosophies that interfere with promoting FCC. But this should not deter them from assuming an active role in FCC. | 6.43 | .535 | 6.00 | 6 |
| 7: In some situations, families feel ignored or burdened with too much independence, while others are marginalised. Conflicting assumptions have been made between nurses and parents about the degree of parent participation during hospitalisation. Therefore, FCC requires well-staffed facilities that carry all responsibilities while allowing flexible and receptive collaborative partnership with families that is overseen and supported by nurses. | 6.71 | .488 | 7.00 | 7 |
| 8: For FCC to be a reality nurses need a clear vision of FCC practice. This can start in nursing education and be followed through. Resources, guidelines, tools relative to practice settings must be available to effectively operationalise FCC that is translational and transferable to all areas, ages and countries. At that point, nurses should experience FCC as it is intended, hence are more likely to internalise it. | 6.86 | .378 | 7.00 | 7 |
| 9: FCC is based on the assumption that, in most occasions, families (extending to include community etc) are their children's primary source of nurturance during childhood while hospitalisation is the temporary event in their lives | 6.43 | .535 | 6.00 | 6 |
| 11: Although FCC is not consistently practiced ideally within and between settings, there needs to be a universally agreed upon template/guideline to operationalise FCC practice that can then be modified by institutions to be culturally safe and/or relevant to their individual setting. | 6.43 | .787 | 7.00 | 7 |
| 12: In some settings, FCC just happens as an unintentional phenomenon. For this ad hoc practice to change, there need to be standards to transfer it into practice. | 6.14 | .690 | 6.00 | 6 |

| | | | | |
|---|---|---|---|---|
| 14: Family-centered care should be holistic covering the psychosocial, physical, emotional needs of the patient and family. It should be part of all the institution's corners. | 6.57 | .787 | 7.00 | 7 |
| 16: Hospitals need to provide conscious and focused educational sessions to support nurses in providing FCC, relying in that on a template to operationalise FCC. | 6.86 | .378 | 7.00 | 7 |
| 18: An interdisciplinary team approach is needed to improve family-centered care | 6.86 | .378 | 7.00 | 7 |
| 19: The solutions to the issues surrounding FCC are not simple; thus, debate and discussion are necessary to assure that family-centered health care remains a priority | 6.71 | .488 | 7.00 | 7 |
| 20: FCC should encompass all ages; it is a philosophy of care that extends to whomever that child, young adult, middle or geriatric aged person deem their family to be. The family should be viewed as part of the care teams whatever ages the patient and whatever the condition. Family is diverse and means different things for different people dependent on country, culture, beliefs, sociopolitical and demographic variables. Therefore, nurses must use their good sense and professional expertise/judgment to decide the best approach for each case. | 6.57 | .535 | 7.00 | 7 |
| 21: A multi-tiered approach needs to be included at all levels to maximise the potential benefits of FCC not only in health care policies but also in the nurse education arena. | 6.14 | .900 | 6.00 | 7 |
| 23: A charter of rights including the families' rights of having a FCC model is a great initiative | 6.29 | .756 | 6.00 | 6 |
| 25: Although models of care should be developed to apply in each setting, facilities/policies should be modified /developed to match the idealistic /theoretical philosophy of FCC. Policies are not permanent and should be changed when the need arises. | 6.29 | .756 | 6.00 | 6 |
| 27: We cannot blame a lack of understanding by health care professionals as a major obstacle hindering the application of FCC if we still lack a consensus and a standardised approach or tool to use within clinical practice | 6.29 | .756 | 6.00 | 6 |

In summary, the results indicate that experts, though differing in their perceptions, are in agreement on many issues related to FCC. Experts agree that there is some ambiguity in the literature regarding FCC. Also, there was agreement that there is an embedded consensus between the international pediatric community on different aspects of FCC application. The variability in experts' reviews and votes demonstrates that it is as difficult to describe and theoretically define FCC as it is to grasp its core. However, experts agreed that FCC can be operationalised using a standard transferable template or guideline that could be modified to suit individual settings. The next step is to test its

applicability and the psychometric properties of a measure of how nurses report these elements in their clinical practice, across settings and across countries.

## Discussion

Although FCC is a well-known, popular model of care that has been studied and referred to in many reports there was little evidence of a single definition of FCC being referred to and evidence suggests that it is not effectively implemented (Shields et al., 2012). Arguably, there is no single and cohesive vision of FCC practice to guide nurses meaning that FCC is used in different ways in different settings based on individual beliefs and views. The statements explored in this study show that although experts in the field may well agree with many statements, some differences remain based on their research and personal experience. A philosophical analysis of FCC (Uniacke et al., 2018) gives some insight into the confusion surrounding the implementation of FCC and provides clues as to why it may be poorly used. FCC is an approach that most nurses working with children support despite the relatively limited knowledge that exists about its efficacy, core characteristics and best means of implementing it in a variety of settings. Experts in this study agreed that, although improved understanding of FCC would be beneficial, the lack a standardised approach to the implementation of FCC within clinical practice due to the absence of robust policies and management plays a major role limits the efficacy of FCC (Coyne et al. 2011).

A useful application of the results from this study would be the development of a tool based on items derived from the statements to measure the “family-centredness" of health professionals’ clinical practice. A validated tool would help measure aspects of FCC and their impact on children and families.

For FCC to be a reality, a clear vision of FCC practice is needed and based on the results of this study, the following recommendations were agreed upon to help guide efforts in this regard:

- FCC requires well-staffed family-appropriate facilities, along with the necessary resources, guidelines and tools.
- Barriers to FCC must be overcome. Barriers can exist at the organisational, environmental and individual levels consequently these need first to be identified in each setting.
- Health care providers must acknowledge and act upon the fact that families are the main stable and permanent source of nurturance for children, while hospitalisation is temporary.
- A universal template or guideline and a set of standards is needed to operationalise FCC and transfer it into practice.
- FCC should be holistic, interdisciplinary, and available across an institution.
- FCC views family as part of the health care team, regardless of the patient's condition or reason for admission to a health service.
- Culture plays an important role in the perception of FCC and what it means in relation to family participation in the child's care and expectations of family involvement. Cultural competence is critical. Because people are diverse, nurses must use their professional expertise and judgment to decide the best approach for each case.
- Different means can be used to foster the application of FCC. While a charter of rights is a good initiative, policies and facilities should be modified to reflect the philosophy of FCC and its major components.
- Children and young people, and parents and family members need to be actively involved in defining, operationalising and evaluating FCC.

### *Limitations*

The results of this consensus study generally demonstrate that the ideal of FCC continues to be supported by health professionals. However, the results are limited as the study does not include the perspectives of children and their families. Experts were drawn from a small pool of experts in FCC who are well known in the field and from a group of interested nurses attending a session at a

research conference, so the results may not reflect the views of the wider population of nurses working with children and their families.

## Conclusion

We used a modified Delphi technique to obtain the perceptions of FCC and its implementation from a group of recognised experts in researching FCC, from a range of countries. Results indicated that even among FCC experts, understandings of FCC differ and that this may account for some of the confusion and conceptual disagreement. The study is the beginning of a programme of research that will explore FCC further, with the aim of understanding why it is so difficult to implement effectively. While the claims about the inefficacy of FCC model in the paediatric population are valid, there is still no legitimate reason to exclude the FCC model from practice, especially in the absence of any credible alternative.

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