

Perceptions of family-centred care: a UK pilot study of the Shields and Tanner questionnaires

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Abstract

The aim of this study was to test the content, reliability, validity, applicability and ease of use of a pair of questionnaires (Shields and Tanner questionnaires) which examine the perceptions of family-centred care (FCC) held by parents of hospitalised children and the staff who care for them. FCC, while a cornerstone of current paediatric practice, is not always implemented effectively, as it depends on the perceptions held by both those who administer it, the staff, and those who receive it, the parents.

In this cross-sectional study with convenience samples in three hospitals in north-east England, five medical students collected, entered, analysed and interpreted the data using SPSS and Cronbach's alpha. The Cronbach's alpha for each questionnaire was 0.79 (staff) and 0.72 (parents). These questionnaires proved to be reliable and valid, easy to use, and were relevant for use in studies about FCC. While the reliability was tested, the samples were not large enough to do any other statistical tests such as factor analysis. This will be part of a subsequent study. This study can now be used for larger studies, the results of which will inform the delivery of care to children and families in hospitals.

Keywords: family-centred care, paediatrics, pilot study.

What is known on this topic

- Family-centred care (FCC) is widely used in paediatrics, though its effectiveness is unproven.
- Effective negotiation between health staff and parents is the key to its successful implementation.
- Perceptions held about FCC by both groups affect implementation.
- The Shields and Tanner questionnaires have been developed to assess perceptions of FCC held by parents of hospitalised children and staff who care for them.

Family-centred care (FCC) is "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 recognised as care recipients"¹. Until the 1960s, many health professionals believed that parents should be excluded during a child's hospitalisation due to firmly held beliefs that the presence of parents was detrimental to children's emotional health^{2,3}. However, FCC is now widely used in paediatrics, though notoriously difficult to implement, with some parents feeling that they are being imposed upon to undertake nurses' work⁴.

What this paper adds

- As a pilot study, this paper addresses the use, reliability and validity of the Shields and Tanner questionnaires.
- In this setting of three hospitals in the UK, the questionnaires were found to be reliable, valid and easy to use.
- They can now be used with confidence for a larger study.

Effective negotiation between staff and parents ensures the effective implementation of FCC⁵. Within the UK's National Health Service (NHS), where this study was implemented, paediatricians and others are encouraged to support FCC and its implementation in clinical practice^{6,7}. In this paper we provide information about a pilot study in three English hospitals regarding the implementation of a set of questionnaires⁸ which were developed in Australia to examine the perceptions of FCC held by parents of hospitalised children and by the health professionals who care for them.

Background

FCC, while a cornerstone of current paediatric practice, has not always been held in such a high regard as it is today. Spitz⁹, Bowlby¹⁰⁻¹³ and Robertson^{14, 15}, in the decades between 1940 and 1980, suggested that the widely supported belief of paediatric health professionals that parents should be excluded during a child's hospital admission was erroneous and damaging to the child¹⁶. It was not until about the 1980s that, in most countries, parents were welcome participants in the care of sick children¹⁷. During this period, models of care delivery passed through several iterations until FCC was devised. This evolution included care-by-parent, partnership in care, negotiated care and finally FCC³.

However, there is little evidence that FCC does or does not work as a model of care, nor that it makes a difference¹⁸. In 1994, Darbyshire¹⁹ adduced that FCC was a wonderful ideal but very difficult to implement successfully. Coyne's²⁰ more recent work demonstrates that this indeed may be true, as she found that parents are becoming resentful at being made to do what they see as nurses' work, and that nurses act as gatekeepers who may or may not allow parents the opportunity to be active participants in their children's care. Similar findings were deduced by Hallström & Runeson²¹ who demonstrated that parents used strategies to ensure they could remain involved in a child's care to the level they themselves chose. Successful communication and negotiation are the keys to successful implementation of FCC⁵, and such can be complicated by philosophical concepts of who feels they 'own' a child – in a hospital ward, such feelings may colour the way care is delivered²².

In the United Kingdom (UK), the NHS controls the vast majority of hospitals and the way they are run. Most hospitals which care for children will, similarly to hospitals in other parts of the world, formally espouse a policy of FCC^{6, 7}, hence FCC is relevant for all health professionals, including nurses, doctors and allied health staff. However, there is a gap in the knowledge of what FCC is²³, what it entails, and how the model works, and differing perceptions between staff and parents leads to difficulties in FCC implementation; this ultimately compromises care of the child and family²⁰.

This paper describes a pilot study²⁴, undertaken in the UK, of a set of questionnaires about perceptions of FCC. One of the questionnaires in the set is for parents of children using health services, and the other for the staff who are caring for them. The set had previously been used in Australia⁸. The aim of the study, of which this pilot is a part, is to examine parents' and hospital staff's attitudes to FCC in the UK, Australia, Israel and Spain, thus providing an international perspective on the use of FCC in health services.

Methods

This project is part of a large, ongoing study which has several branches, such as a Cochrane systematic review²³, a survey of the needs of parents²⁵⁻²⁷, FCC in developing countries²⁸, and

in adults²⁹. In addition, the questionnaires are being used in several countries; this will allow conclusions to be drawn about the validity of the tools, as well as the applicability of FCC from an international perspective. The aims, of the arm of the study for which this is a pilot, are to: examine attitudes of staff (nurses, doctors and allied health staff) about FCC; examine attitudes of parents of hospitalised children about FCC; and compare responses from parents and staff. Once testing of the tools is completed, this study will be undertaken. Ethical approval for this pilot study was granted by the local area health research ethics committee (REC No. 06/Q1104/26).

The instruments

The questionnaires were developed in Australia⁸, and the questions were based on two studies – one in the US³⁰, and another in the UK³¹ – which examined concepts and elements of the FCC model. In the US, Galvin *et al.*³⁰ developed a questionnaire for parents of hospitalised children, in which respect, collaboration and support provided the framework for the development of the questions. Hutchfield³¹ in the UK, using concept analysis, developed themes of respect for parents, collaboration, shared decision making, and effective communication to develop a questionnaire for nursing students and practising nurses. The set of questionnaires here, called the Shields and Tanner questionnaires⁸, were based on these studies. We describe the pilot study of the Shields and Tanner questionnaire⁸ in the UK, including their reliability as well as ease of use, relevance and practicalities of use in UK health services. This project was used to teach medical students the exigencies of social science research as well as the tenets of FCC²⁴.

Another short scale was added to address staff perceptions of FCC. This was taken from another questionnaire used in the UK before³² (Cronbach's alpha 0.8). These comprised a scoring system using semantic differentials^{33, 34} in which adjectives and their antonyms are placed at opposite ends of a scale and people are asked to place a cross on the part of the scale that best reflects their acceptance or rejection of that adjective in relation to the topic under examination. The differences in the mean scores can be tested using a t-test. We used a 10-scale set of adjectives, which allows for easy calculation of the mean score, and the statements to which the adjectives pertained were "I find working with children..." and "I find working with parents...". The theory behind these statements is FCC – its successful application would dictate that no significant differences would be found between the two scores.

In the Australian development of the two questionnaires⁸, one for parents of hospitalised children and one for staff (slightly modified from the parents'), the scales yielded a Cronbach's alpha score of 0.72-0.79 respectively. To ensure content validity, an Australian 'panel of experts' comprising two paediatric nurses, one paediatrician and two parents examined the questionnaires.

As part of the pilot study in the UK, a panel of experts consisting of two paediatric nurses, a paediatrician and two parents, made some slight modifications in the brief questions about the demographics of the sample, and assessed the questions for their relevance in the UK setting. No changes were made to the questions about FCC.

Sample size

The questionnaires were distributed at three general hospitals with children's wards in north-east England. Each hospital served a NHS Trust (health service district) in similarly socially disadvantaged areas. One hospital had two children's wards, while the others had one. They were secondary hospitals, and tertiary referral cases were sent to the same tertiary referral paediatric service about 50 miles away.

As a pilot study, practicalities such as availability of subjects within areas and time constraints determined the convenience sample of 10 parents and 10 staff at each hospital (Table 1). While the questions in the tools were similar, no direct linking of parent-staff answers were possible; in future work, this may be undertaken. The staff in each ward were looking after the children from whom the parent sample was drawn.

Return rates were influenced by the ability of the researchers (the first five authors) to wait for the questionnaires to be completed. At one hospital, double the number of questionnaires was distributed to achieve the required number; at another, the students collected 20 completed questionnaires with no difficulty. Data were entered as the questionnaires were collected. Response rates are shown in Table 1 – they ranged between 30-100% for each hospital, giving a total of 56% for the parents and 60% for the staff sample.

Specific inclusion criteria included, for parents, that they must have a hospitalised child, and for staff that they must work in the areas where those children were nursed. Exclusion criteria included parents of children who were terminally ill, and/or who were admitted to intensive care units, and those whose admission were for child protection issues and, for staff, that they cared for those particular children. It was felt that parents in these difficult situations would have different perceptions of FCC than parents in less critical areas, and so it was unethical to ask them to complete questionnaires. They may, however, be included on ongoing studies once the psychometric testing is complete. These families were not included in Galvin's study³⁰.

Table 1. Sample sizes and response rates.

Hospital	Parents		Staff	
	Distributed	Returned (%)	Distributed	Returned (%)
1	10	10 (100)	10	10 (100)
2	30	10 (30)	30	10 (30)
3	20	14 (70)	10	10 (100)
Total	60	34 (57)	50	30 (60)

Statistical analysis

The students who were involved in this pilot study undertook the data analysis under supervision. Cronbach's alpha was used to determine reliability for both the questionnaires. Because of the small sample size, no other statistical tests were undertaken as they would have been meaningless. No correlation was possible with the demographic characteristics of the samples. Factor analysis and principal components analysis will be undertaken in the main study using a much larger sample size.

Results

A total of 34 parents completed questionnaires (including both parents from one family) (Table 2). Most were female, possibly reflecting the fact that it is most commonly mothers who accompany their children in hospital. Sixty-nine percent of the sample ranged in age from 25 to 40 years, and 12% were single parents. All the families had children other than the admitted child, with 56% having two or more other children. Most of the admitted children (66%) were under 5 years of age, and the majority of the sample took under an hour to travel to the hospital. Socio-economic status was not included, nor was educational attainment. While these would have added to the study and may be included in future work, because of the similar nature of the areas from which the samples were drawn it was not deemed necessary, nor appropriate, at this pilot study stage, to ask such questions.

Of the staff sample of 30, most were female (83%), consistent with the predominantly female workforce found in hospitals. Ages ranged from 18 to over 50 years, with just over half under 35 years of age. While we did not ask the occupation of the staff member, 40% of the sample was educated to diploma level, while 33% had a degree, either undergraduate or postgraduate. Only 10% of the staff sample had been working with children less than 2 years (Table 3).

Analysis of the questionnaires using Cronbach's alpha showed that the questionnaires were reliable, with 0.79 for the staff questionnaire, and 0.72 for the parent's questionnaire. The semantic differential scales yielded Cronbach's alpha of 0.8.

Discussion

This was a pilot study to test the reliability and validity of two questionnaires⁸ which examined parents' and staff's perceptions of FCC in three hospitals in the UK. Content validity, after some minor changes of the demographic questions for the UK context, was sound as demonstrated through the applicability of the questions for use in paediatric care, and their relevance to the understanding of FCC. The health professionals who were on the expert panel agreed that the concepts under examination were relevant to practice, and the parents on the panel felt that the questions reflected their experiences of health service for their children. The sample sizes were not large enough to undertake factor analysis or principles components analysis, but standardised tests using Cronbach's alpha demonstrated

that the questionnaires were reliable and were consistent with the reliability testing on the questionnaires on which these were based^{30,31}.

Similarly to the first pilot of these tools in Australia⁸, these questionnaires were easy to use, and the technique for capturing a convenience sample was equally so²⁴. The reliability demonstrated in this set of tools means that they can be effectively used for a larger study, and further statistical analysis will provide a more comprehensive exploration of their fittingness and usability. This project was conducted in the UK, and a full study is planned there. The questionnaires are at present being used in Spain (after translation into Spanish) and will be used in Israel. A large project, which will include comprehensive psychometric testing, is beginning in Australia and, once this is done, it will provide a level of confidence that the tools do measure perceptions of FCC.

Limitations

At this stage, it was not practical to collect enough questionnaires to allow for factor analysis, which would

Table 2. Demographic characteristics of parents (n=34).

	Frequency	%
Age		
<18	2	6
19-24	7	20
25-30	3	10
31-40	20	58
41-50	2	6
Sex		
M	6	18
F	28	82
Single parent		
Yes	4	12
No	30	88
Other children in family		
1	6	17
2	19	56
3	5	15
4	2	6
>4	2	6
Age of admitted child*		
<1	8	24
2-5	14	43
6-10	6	18
11-15	4	12
>15	1	3
Time taken to travel to hospital		
<1 hour	33	97
>1 hour	1	3

* Both parents from one family completed separate questionnaires

validate the questionnaires more thoroughly than Cronbach's alpha. A convenience sample was appropriate for this study, but no attempt to generalise findings is feasible. Even when the full study is undertaken, it may not be practicable to collect more than a convenience sample. Further, in the pilot, we did not ask staff their occupational group; this will be done in the main study as it may yield interesting perspectives.

Implications for practice and research

As this was a pilot study, few conclusions can be drawn, except to say that the questionnaires can now be used for a larger study, while further psychometric testing will be undertaken to generate further confidence. Until the larger study is done, it is not possible to discuss implications for practice. However, a pilot study such as this provides evidence of the effectiveness of the tool that can be used for future research.

FCC as a cornerstone of paediatric practice is still untested²³. To demonstrate real effectiveness of such a model will require a properly conceived and planned randomised control trial to provide level two evidence, and meta-analyses to generate level one evidence. This will be difficult, though not impossible, but will require substantial funding over a long period of time. During difficult economic times, health research funds must be distributed wisely, and funding bodies are possibly more likely to see a higher value in funding projects that will give substantial evidence within a short time. Research about sociological concepts such as FCC as a way of caring children in hospital is a less tangible concept to investigate than, for example, genomics or a vaccine for influenza viruses.

Table 3. Demographic characteristics of staff (n=30).

	Frequency	%
Age		
18-25	6	20
26-30	7	23
31-35	4	13
36-40	5	17
41-50	5	17
>50	3	10
Sex		
M	5	17
F	25	83
Level of education		
Certificate	8	27
Diploma	12	40
UG degree	6	20
PG degree	4	13
Length of time working with children		
< 2 years	3	10
2-5 years	9	30
6-10 years	8	27
> 10 years	10	33

However, this does not mean that topics such as FCC are not important, and health professionals interested in the care of children in hospital must continue to apply for grants for projects such as this. In the meantime, we can build up evidence that will eventually contribute to ways to conduct the randomised controlled trials which will provide the level two evidence necessary to fully demonstrate the efficacy of FCC. Instruments to investigate and measure perceptions of FCC will be part of this, and studies of which this pilot is part would use such instruments.

Conclusion

As part of a learning exercise for students, the techniques for data collection, entry and statistical analysis provided experience in social science research. The Shields and Tanner questionnaires were given out in three hospitals in England to parents of hospitalised children and the staff who cared for them. The small sample size precluded any statistical analysis other than demographic descriptions and Cronbach's alpha determinations, but these, along with the content validity attested to by the panel of experts of health professionals and parents independent of the study, provided results which allowed confirmation of the tools as reliable, practical and easy to use.

This pilot study, using a small convenience sample of staff and parents, demonstrated the reliability and validity of tools which can now be used in the main study about perceptions of FCC held by parents of hospitalised children, and the staff who care for them.

Acknowledgements

We thank Dr Steve Killick and Ms Gwen Irving from Hull York Medical School, and all the staff and parents at the three hospitals who so kindly completed questionnaires and gave freely of their time.

Manuscript preparation

No funding was received for this study. Ethical approval was obtained from REC No. 06/Q1104/26; the guarantor was LS. Conceived idea and planned project: LS. Data collection and analysis: SA, PC, SK, SR & LW. Prepared manuscript: LS. Reviewed and corrected manuscript: all authors. Note that LS is Editor of this journal.

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