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ARTICLE

Parent and staff perceptions of family-centered care in two Australian children's hospitals

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Abstract

Aim: This paper is a report of the comparison of perceptions of family-centred care by hospital staff (nurses, doctors and allied health staff) and parents of hospitalised children in 2 Australian tertiary paediatric hospitals.

Background: Family-centred care is an accepted approach to caring for children and their families in hospital. Previous publications have been inconsistent, ranging from promoting its benefits and integration into practice, reporting operational difficulties and proposing that family-centred care may not be working at all. An evaluation of the model of care is long overdue.

Method: A quantitative comparative cross-sectional survey was used to collect data in 2010 from a convenience sample of 309 parents of hospitalised children and 519 staff. Participants rated 20 items grouped into 3 subscales of respect, collaboration and support.

Findings: Both parents and staff responses were positive and parents had significantly higher subscale scores for respect, collaboration and support (all $p<0.0001$). Parents' responses for 19 of the 20 items were significantly higher than for staff. The item on which parents and staff did not differ was concerned with being able to question recommendations about the child's treatment.

Conclusion: Both parents and staff had positive perceptions of their family-centred care experiences. Parents' perception of their experience was more positive than staff perceptions of their delivery of family-centred care in hospital. Whilst the positive experience by both consumers and healthcare providers is an important finding, reasons for differences, in particular in supporting parents, require further examination.

Keywords

Allied health staff, doctors, family-centred care, hospital, nurses, parents, perceptions, person-centeredness

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Introduction

Family-centred care (FCC) is a concept used to describe the approach to caring for children and their families within health services in which care is planned around the whole family, not just the individual child or young person and in which all the family members are recognised as care recipients [1]. The main element of FCC is the involvement of the parents in a child's care.

One of the first to critique FCC, Darbyshire [2] proposed that the complexities of FCC had been minimised in the literature and that while FCC was the optimal approach to care, in reality, it was difficult to implement. During a child's admission, parents who parented in front of the nurses felt they were "parenting in public" while nurses who nursed the children in front of their parents felt they were "nursing in public" [2]. As reported in subsequent reviews of FCC or parental participation in care [3-5] and by several other investigators [6-11], Darbyshire [2] found that this was compounded by the judgemental attitudes of some nurses towards parents and suggested that, for FCC to succeed, understanding and empathetic communication between parents and nurses were necessary.

The Institute of Patient and Family-Centered Care [12] identified the core concepts of FCC as dignity and respect, information sharing, participation and collaboration. A concept analysis of FCC nursing care of hospitalised children reported that while there was agreement on the defining attributes of the FCC concept, other aspects or terms used to describe it remained unclear [13]. Other terms that have been used to convey the FCC concept have included: "parental participation" (which means that accompanying parents are involved in undertaking aspects of the care of their hospitalised child) [2], "care-by-parent" (where parents are housed with the sick child in a purpose built unit which resembles the home) [14] and "partnership-in-care" (in which parents and nurses work together to provide care for the sick child) [7]. Recently "negotiation of care" as a method to achieve FCC has been examined from the perspective of parents and nurses [15-17].

These models of care were precursors to the formalised model of FCC and all have collectively contributed to this ubiquitous, though unsubstantiated, cornerstone of current paediatric practice [18]. Once FCC became accepted as a concept, investigators began to examine its component parts. Galvin *et al.* [19] found that parents rated respect, collaboration and support as critical elements of a FCC philosophy, while Hutchfield found similar themes amongst staff responses [20]. These studies became the basis for the development of instruments to measure perceptions of FCC held by health professionals and parents [21] and used in this present study. They are explained in detail later.

Young and colleagues [16,17] found that gaps existed between nurses' assumptions and parental attitudes and priorities. In an attempt to measure health professionals' attitudes to FCC, Shields and colleagues, in a series of studies conducted in Indonesia, Thailand, the United Kingdom (UK) and Australia, compared ratings given by nurses, doctors and allied health staff to working with children and their parents [10,22-24]. In all countries, professional staff rated working with children significantly higher than they rated working with parents. While this is not surprising given that people choose to work in paediatrics because they enjoy working with children, it is not congruent with a FCC philosophy or policy, in which the children and parents are treated as a single integrated unit. A Cochrane systematic review of FCC [18] found no eligible studies, thus no conclusions about its effectiveness or appropriateness as a model of care for children and families could be drawn. Many difficulties in FCC centre around communication and lack of knowledge regarding how the model works, together with differing perceptions, leading to a misalignment in interactions between parents and staff [3,8,9,25,26]. Only when such differences can be identified and resolved can FCC be successfully implemented to improve the care of children and families in health services [27].

Broadening the context beyond the paediatric setting, a study of a FCC intervention in Australian adult intensive care units found that it was well received by patients, relatives and staff [28] with measurable improvements in patient outcomes [29]. There appears to be increasing interest in family and person-centred models of care and a draft discussion paper entitled "Patient-centred care: improving quality and safety by focusing care on patients and consumers" [30] provided recommendations and sought public feedback. Recommendations included standardising and utilising survey tools to assess healthcare service experiences of patients and their families. While FCC remains untested [27], it has been expressed in different ways and concerns have been raised about its implementation and effectiveness [27], it appears in many policy documents in paediatric health facilities as an integral part of their philosophies [31,32].

In summary, the plethora of publications surrounding FCC is inconsistent, ranging from promoting the benefits of FCC and its integration into practice, reporting operational difficulties and proposing that FCC may not be working at all. An evaluation of the FCC model of care is long overdue, in particular to determine whether staff views are aligned with the views of parents. This large study, undertaken in Australia, compares parent and staff perceptions of FCC in 2 inpatient tertiary paediatric settings.

Methods

Aims

1. To examine perceptions about FCC held by hospital staff (nurses, doctors and allied health staff)
2. To examine perceptions about FCC held by parents of hospitalised children
3. To compare responses of parents and staff

Design

A comparative, cross-sectional survey of parents and staff was conducted in 2 tertiary paediatric hospitals using the Perceptions of Family Centred Care – Parent (PFCC-P) and Perceptions of Family Centred Care – Staff (PFCC-S) instruments. The 2 instruments were initially tested for clarity, internal consistency and content validity.

Setting

Both hospitals are large paediatric tertiary referral centres in Australia: Princess Margaret Hospital for Children (PMH), Perth, Western Australia and the Royal Children's Hospital (RCH), Brisbane, Queensland. They both provide paediatric care for similar populations in Australia's 2 geographically largest states, serve wide areas of remoteness and have large rural as well as metropolitan catchment areas and their activities and throughput are comparable. Similar, although not identical, FCC models of care are practiced at the hospitals.

At PMH, the diversity of the families who require the hospital services are acknowledged in the model of care. As a result, the aim is to deliver care that encompasses the core concepts of FCC in an environment that promotes healing, trust, respect and wellness. Family-centred care is delivered using the key principles of respect, information sharing, collaboration and empowerment. By staff fulfilling the practice guidelines, families will feel empowered to make informed decisions. Families have the right and the authority to care for their children. The core concepts of FCC empower families in the care of their children.

Royal Children's Hospital acknowledges the core concepts as identified by the IPFCC [12] as underpinning the organisational value of FCC. Specifically, the model states 'Family-centred care is central to who we are as an organisation. It acknowledges that the family is the constant in a child and young person's life and reflects our commitment to partnering with families in our pursuit of best possible healthcare outcomes for children and young people'. The 7 operating principles of Partnership, Trust, Participation, Transparency, Collaboration, Empowerment and Flexibility explain how the core value of FCC is delivered at the RCH. In this model, patients and families define their families and kinship groups, similarly to IPFCC [12].

Instruments

The PFCC-P and PFCC-S consist of 20 items that are closely matched, with some questions worded slightly differently to allow for the context of the specific group; for example, item one in the parent instrument is worded "when I come to the hospital I feel welcome" and in the staff instrument is worded "when parents come to the hospital they are made to feel welcome". Responses require participants to mark a box on a 4-point scale that best expresses the participant's experience. The 4 points were labelled: never, sometimes, usually and always. In addition to the 2 FCC scaled instruments, demographic details were collected for each group.

The PFCC-P and PFCC-S instruments were originally developed, validated and underwent preliminary testing by Shields and Tanner [21] based upon items used by Hutchfield [20] and Galvin *et al.*[19], to measure and compare perceptions of FCC held by parents and staff. Within each PFCC scale, the 20 items formed 3 subscales: respect, collaboration and support. The first subscale of respect included 6 items that acknowledged the rights of families in hospital. The second subscale of collaboration reflected the recognition of the partnership role of parents in caring for their child and comprised 9 items. The third subscale of support included 5 items to describe staff demonstrating support of the families' needs, while the child was in hospital. Cronbach's alpha reliability coefficients of 0.72 for the parent version and 0.79 for staff version have previously been reported for the FCC instruments across the 3 subscales [22,23].

Validity and reliability of instruments

Minor amendments were made to the wording of some items in the FCC instruments to ensure they matched the clinical context. To ensure content validity, apparent internal consistency and content validity of the FCC instruments, a "panel of experts" examined each instrument, including the demographic questions, collectively called the "questionnaire". As recommended by Aamodt [33], raters were drawn from the context within which the original data were generated. The panel comprised 6 parents for the parent questionnaire and 6 staff (two nurses, two medical staff and two allied health staff) for the staff questionnaire [34]. The testing process used the methods described by Imle and Atwood [35] for assessing content validity, apparent internal consistency and clarity of the questionnaire. Three questions were addressed in this pilot testing phase:

1. To what extent are the items in the instrument clear?
2. To what extent does the scale evidence apparent internal consistency? (the term used by Imle and Atwood [35] to describe non-quantitative assessment of homogeneity of content).
3. To what extent do the constructs evidence content validity?

Participants were given a pack containing with a covering letter, a study information sheet, the instrument and an instruction and response sheet to rate the clarity, apparent internal consistency and content validity of the questionnaire. All questionnaires were completed without any missing data.

No items were judged to be redundant. While there were some individual comments about completion of the demographic questions and interpretation of the FCC items, each panel reached agreement of at least 83% for all items. No changes were made to items in the questionnaires.

Participants

The convenience sample comprised parents of hospitalised children and the nurses, doctors and allied health staff who cared for them at PMH and RCH. Participants were recruited from PMH and RCH. For inclusion, participants had to be able to read and write English.Parents had to have a child in hospital and staff to be working in areas where children were inpatients. Parents of children admitted with child protection issues and nursing staff employed through agencies were excluded.

Sample size

The primary objective of the study was to compare parent and staff perceptions on the 3 subscales (respect, collaboration and support) comprising the PFCC instruments. A mean difference between parents and staff of at least 10% of the rating scale was considered important. This corresponds to an absolute difference of 0.3 on the rating scale. In a previous study [21], scale scores (individual averages of ratings on relevant items) were approximately normally distributed with standard deviations of 0.4 or less. Assuming a Type I error probability of 0.017 (overall alpha of 0.05 with Bonferroni adjustment for comparisons on 3 subscales), we estimated that responses from 49 parents and 49 staff would allow us to detect a mean difference of 0.3 with 90% power. However, because we planned to collect sufficient data to examine the psychometric properties of the PFCC instruments (to be reported separately), we recruited as many parents (n=309) and staff (n=519) as possible over the study recruitment period.

Data collection

Two research assistants (RA), one at each hospital, recruited parents and staff between March and June 2010. Each RA recruited parents by visiting the wards/departments where their children were inpatients. Parents were given information sheets and time to consider if they wanted to participate in the study. Those who agreed to participate signed a consent form and were given the questionnaire, which, on completion, was collected by the RA or returned by internal mail. Staff were recruited through ward based advertising, by internal mail using staff rosters and at ward/department meetings. Completed staff questionnaires were collected by the RA or returned by internal mail.

Data analysis

Demographic characteristics of parents and staff are reported as frequency (percent), mean (standard deviation) or median (interquartile range). Parents and staff were compared on categorical characteristics using chi-square tests and on numeric characteristics using Wilcoxon Rank Sum tests. Family-centred care subscale scores for parents and staff were not normally distributed and were compared using Wilcoxon Rank Sum tests with Bonferroni adjustment to control Type I error. Secondary analyses compared PFCC ratings for parents and staff on the individual instrument items using Wilcoxon Rank Sum tests. All statistical tests were 2-tailed. Cronbach's alpha was used to examine the reliability of the PFCC subscales.

Ethical considerations

Ethical approval was given by the human research ethics committees of: Curtin University (SON&M 30-2009), Princess Margaret Hospital for Children (1709/EP) and the Children's Health Service District (HREC/10/QRCH/10). Written consent was obtained from parents and for staff, consent was implied by return of the completed questionnaires.

Results

Response rates

Parents: A total of 374 questionnaires were distributed to parents (PMH n=200, RCH n=174), with a total of 309 returned (PMH 168, 84%; RCH 141, 81%). This represented an overall response rate of 83%. There were 239 parent questionnaires with complete data on the PFCC-P instrument (PMH n=124, RCH n=115).

Staff: 850 questionnaires were distributed to staff (n=PMH 474, n=RCH 376), with 519 returned (PMH 279, 59%, RCH 240, 64%). This represented an overall response rate of 61%. There were 467 staff questionnaires with complete data on the PFCC-S instrument (PMH n=255, RCH n=212). Of the staff questionnaires, 276 were distributed to medical staff (PMH 167, RCH 109), 350 distributed to nurses (PMH 237, RCH 113) and 149 distributed to allied health staff (PMH 80, RCH 69).

Table 1 Demographic characteristics of parents and family

	Frequency	*(%)*
Age (n=238)		
Up to 30 years	57	19
31- 45 years	203	66
46 years or more	47	15
Sex (n=236)		
Male	36	15
Female	200	85
Level of education (n=236)		
Up to high school	86	36
Technical qualification	68	29
University degree	46	20
Postgraduate qualification	31	13
Other	5	2
Main place of residence (n=230)		
Metropolitan	142	62
Regional/ remote	88	38
Inpatient area (n=234)		
Oncology/haematology	23	10
Surgical	96	41
Medical	62	26
Chronic / long term	42	18
Not coded	11	5
Child been in hospital before (n=236)		
Yes	166	70
No	70	30
Previous inpatient experience with another child (n=237)		
Yes	196	83
No	41	17
When child is going home (n=235)		
Today	83	35
Tomorrow	23	10
This week	25	11
Don't know	104	44

Note: n = number of responses for each characteristic

Medical staff returned 149 (response rate 54%), nurses returned 221 (response rate 63%) and allied health staff returned 119 (response rate 80%) questionnaires.

Demographic characteristics

Parents: Parent and family characteristics are detailed in Table 1. Most parents were female (200, 85%), between 31 and 45 years (203, 66%), had attained technical or tertiary level qualifications (145, 61%) and lived in the metropolitan area (142, 62%). Most families comprised 3 children or less (203, 85%).

Table 2 Demographic characteristics of staff

	Frequency	*(%)*
Age (n=465)		
Up to 30 years	172	34
31- 45 years	223	43
46 years or more	119	23
Sex (n=466)		
Male	88	19
Female	378	81
Level of education (n=457)		
University degree	337	74
Postgraduate qualification	120	26
Specialist paediatric qualification (n=466)		
Yes	176	38
No	290	62
Current inpatient area of practice (n=464)		
Oncology	57	12
Surgical	127	27
Medical	158	34
PICU/HDU[a]	38	8
Mixed	73	16
Chronic/long term	3	1
Neonates (PMH staff only)	8	2
Years of paediatric or neonatal experience (n=462)		
Mean 11.6 years (SD± 9.8) Median 10 years (<1 – 43)		

Note: n = number of responses for each characteristic
[a] PICU/HDU = Paediatric Intensive Care Unit / High Dependency Unit

Most parents reported their hospitalised child had at least one previous admission to the hospital (166, 70%), with 83% reporting a previous experience in hospital with another child. The mean age of the hospitalised child was 7.1 years (SD ± 4.8), median 6 years (min 22 days – max 21 yrs). Families were distributed across participating ward areas with disease/condition/reason for admission categorised into: oncology/haematology 23 (10%), surgical 96 (41%), medical 62 (26%), chronic/long term 42 (18%), other 5%. The mean length of time the child had spent in hospital this admission was 10 days (SD ± 43), median 2 days (range < 1 – 392). While 83 (35%) were expecting to be discharged that day, almost half the parent sample (104, 44%) did not know when their child would be going home.

Staff: Table 2 provides demographic characteristics for participating staff. Most were female (81%) reflecting the predominantly female nursing and allied health workforce and the increasingly female medical workforce. Of respondents, 174 (34%) were aged 30 years or less, 223 (43%) were aged between 31-45 years, 119 (23%) aged 46 years or more, reflecting the age of the contemporary health workforce (World Health Organization, 2011). The mean number of years staff reported that they had been working in a paediatric or neonatal setting was 11.6 (SD ± 9.8), median 10 years (range < 1-43).

Staff worked in a variety of practice settings within both hospitals: oncology (57,12%), surgical (127, 27%), medical (158, 34%), intensive care/high dependency (38, 8%), mixed (73, 16%), chronic/long term (3, 1%), PMH neonates (8, 2%). One-hundred and twenty (26%) staff held postgraduate qualifications and over a third (176, 38%) reported that they held a specialist paediatric qualification. While the range of years of staff experience is wide, this was an experienced and well-qualified sample of staff who provided their perceptions of FCC with a mean of almost 12 years (SD ± 9.8); median 10 years (range <1-43) of experience working in a paediatric or neonatal setting.

Estimation of instrument reliability

Cronbach's alpha for the parent instrument was 0.63 for the respect subscale, 0.78 for the collaboration subscale and 0.85 for the support subscale. The corresponding values for the staff instrument were 0.71 for the respect subscale, 0.78 for the collaboration subscale and 0.71 for the support subscale.

Parent and staff perceptions

Responses to the FCC items were numerically coded as follows: never = 1, sometimes = 2, usually = 3 and always = 4. For each respondent, a mean score was calculated for respect (average response for 6 items), collaboration (average response for 9 items) and support (average response for 5 items). Negatively worded items (items 5 and 15 on the parent instrument and item 15 on the staff instrument) were reverse coded before calculating the subscale scores. These individual mean subscale scores provided raw data for analyses comparing parent and staff perceptions. Table 3 shows the mean and median subscale scores for parents and staff. Parents had significantly higher subscale scores for respect, collaboration and support (all $p<0.0001$). There was an absolute difference of at least 0.3 between parents and staff scores for 2 subscales, collaboration and support, as well as for the overall scores, where 0.3 corresponds to 10% of the rating scale.

Table 4 shows the mean and median scores for parents and staff on the 20 FCC items. As would be expected from the mean and median subscale scores, parents had significantly higher scores for 19 of the 20 FCC items. The item on which parents and staff did not differ was "being able to question recommendations about the child's treatment". There was a difference of at least 0.3 between

Table 3 Comparison of parent and staff perceptions comparison by subscale and overall

Sub scale	*Parents mean (SD)*	*Parents median (IQR)*	*Staff mean (SD)*	*Staff median (IQR)*
Respect	3.61 (±0.38)	3.67 (3.3-4.0)	3.39 (±0.39)	3.5(3.17-3.67)
Collaboration	3.49 (±0.42)	3.56 (3.3-3.78)	3.19 (±0.37)	3.22(3.0-3.44)
Support	3.19 (±0.60)	3.20 (2.8-3.6)	2.75 (±0.38)	2.80(2.4-3.0)
Overall	3.45 (±0.39)	3.55 (3.25-3.7)	3.14 (±0.32)	3.15(2.95-3.4)

Note: Wilcoxon Rank Sum test p< 0.0001 for all parent-staff comparisons
Scale: Never = 1 Sometimes = 2 Usually = 3 Always = 4, IQR Interquartile range

parent and staff scores for items 2, 6, 7, 9, 12, 13, 15, and 16-20 (0.3 corresponds to 10% of the rating scale).

Discussion

This large-scale study explored perceptions of FCC held by parents and health professionals. Strengths of the study included the use of matched parent and staff instruments that allowed for direct comparisons of FCC perceptions. The high participant response rates suggest the sample is likely to be representative of their respective populations.

The key finding to emerge from this study was that parents and staff positively perceived that FCC was practised in the inpatient setting of 2 large Australian tertiary paediatric hospitals. Further, it was perceived that the core elements of FCC were being practiced, thereby reflecting hospital policies [31,32]. Interestingly, although both parents' and staffs' total responses were positive, parents had significantly higher subscale scores for respect, collaboration and support. An important difference (at least 10% of the rating scale) was found for both the support and collaboration subscale scores as well as for the overall score.

Of the 3 subscales, both parent and staff mean and median values were higher for respect than for collaboration and were lowest for support. The support subscale reflected the provision of emotional care given by staff to parents, which is a fundamental or key aspect in the delivery of FCC. In addition, supporting the parental role itself is equally important [13]. The finding that both parent and staff perceptions of the support subscale were less positive than for the subscales of respect and collaboration could be interpreted as either a strength or a weakness in the provision of support to parents. It could be that staff showed insight by not making presumptions about knowing what parents were going through or it may mean that this aspect of providing FCC requires further attention in order to improve the FCC experience for parents.

Parents' responses for individual items were significantly higher than staff responses for all but one of the 20 FCC items. This item related to parents being able to question recommendations about their child's treatment and could be an aspect of FCC to target for improvement to service delivery [9]. Importantly there was a difference of at least 0.3 (10% of the scale) for more than 50% of the items spread across the 3 subscales: items 2 and 6 in the respect subscale, items 7, 9, 12, 13, and 15 in the collaboration subscale and all items in the support subscale.

A number of possible reasons exist for the differences found; parents' experience of FCC may be more positive than staff appreciate, staff may not fully understand what parents expect in their interactions with staff or perhaps staff perceptions of their own performance falls below their expectations of themselves, particularly in the area of providing support to parents. This reflects similar findings in previous studies in this area [36]. In addition, given that staff had cared for countless families, their experiences of providing FCC was extensive. In comparison, although most parents had a previous experience in hospital with that child (70%) or siblings (83%), the parents' personal experience of receiving FCC in hospital was more limited. This may have resulted in staff averaging their experiences to indicate an overall more general and possibly less positive perception than parents. Further qualitative investigation may be able to account for these differences and advance our understanding about whether we should in fact expect parent and staff perceptions to be similar [37].

Study limitations

Participants were English-speaking parents of children who were hospitalised in one of two tertiary paediatric hospitals and the staff who cared for them. Because of the specialisation of the tertiary paediatric hospitals, it may not be appropriate to generalise these findings more widely to other settings. As data were not collected from non-English speaking parents, their perspectives of FCC are not reflected [4]. Nurses', doctors' and allied health staff's responses were reported as total staff perceptions as this was the focus of this paper. It may be that the different health professionals' perceptions were not the same as each other and this warrants further exploration.

Table 4 Comparison of parent and staff perceptions comparisons by item

Item[a]	*Parents mean (SD)*	*Parents median (IQR)*	*Staff mean (SD)*	*Staff median (IQR)*	*p value*[b]
Subscale: Respect (6 items)					
1.When I come to hospital I feel welcome	3.62 (±0.60)	4 (3-4)	3.33 (±0.58)	3 (3-4)	<0.0001
2. Other members of my family are welcome to attend with me at the hospital	3.71 (±0.52)	4 (3-4)	3.21 (±0.63)	4 (3-4)	<0.0001
3. I am able to be with my child during procedures	3.49 (±0.67)	4 (3-4)	3.21 (±0.68)	3 (3-4)	<0.0001
4. I am able to question recommendations about my child's treatment	3.63 (±0.61)	4 (3-4)	3.61 (±0.59)	4 (3-4)	=0.4287
5. I feel like a visitor (rather than a parent) when I come to the hospital	3.43 (±0.94)	4 (3-4)	3.57 (±0.55)	4 (3-4)	<0.0001
6. My child's privacy and confidentiality are respected	3.77 (±0.53)	4 (4-4)	3.43 (±0.62)	4 (3-4)	<0.0001
Subscale: Collaboration (9 items)					
7. I feel prepared for discharge / referral to other community services after my child's discharge	3.37 (±0.77)	4 (3-4)	3.01 (±0.670	3 (3-3)	<0.0001
8. I am given honest information about my child's care	3.7 (±0.54)	4 (3-4)	3.49 (±0.56)	4 (3-4)	<0.0001
9. I know who to call after I get home if I need help or reassurance	3.53 (±0.74)	4 (3-4)	3.22 (±0.71)	3 (3-4)	<0.0001
10. When decisions are made about my child's care the staff include me	3.48 (±0.72)	4 (3-4)	3.31 (±0.64)	4 (3-4)	<0.0001
11. I am taught what I need to know about my child's care	3.59 (±0.67)	4 (3-4)	3.41 (±0.58)	3 (3-4)	<0.0001
12. I know the name of the doctor in charge of my child's care	3.62 (±0.66)	4 (3-4)	3.25 (±0.66)	3 (3-4)	<0.0001
13. I understand the written material that has been given to me	3.67 (±0.59)	4 (3-4)	2.93 (±0.52)	3 (3-3)	<0.0001
14. My family is included in my child's care	3.40 (±0.79)	4 (3-4)	3.34 (±0.65)	3 (3-4)	=0.039
15. I feel overwhelmed by the information given to me about the child	3.05 (±0.94)	3 (3-4)	2.74 (±0.54)	3 (3-3)	<0.0001
Subscale: Support (5 items)					
16. The staff are familiar with my child's individual needs	3.29 (±0.73)	3 (3-4)	2.94 (±0.51)	3 (3-3)	<0.0001
17. The staff listen to my concerns	3.52 (±0.67)	4 (3-4)	3.20 (±0.55)	3 (3-4)	<0.0001
18. I get to see the same staff	3.01 (±0.72)	3 (3-3)	2.48 (±0.55)	2 (2-3)	<0.0001
19. The staff know who my support people are	2.90 (±0.90)	3 (2-4)	2.43 (±0.56)	2 (2-3)	<0.0001
20. The staff understand what my family and I are going through	3.21 (±0.79)	3 (3-4)	2.72 (±0.60)	3 (2-3)	<0.0001

[a] Item labels are from the parent instrument (PFCC-P). The same items with minor rewording (mainly replacing "I" and "the staff" with "Parents" appeared on the staff instrument (PFCC-S) [b] p values are from the Wilcoxon Rank Sum test, IQR interquartile range

Conclusion

This large, cross-sectional Australian study has shown that both parents and staff (nurses, doctors and allied health) experiences of FCC in the setting of tertiary paediatric hospital inpatient care were positive and that practice appeared to reflect the FCC policies in place. The finding that parents had more positive perceptions of their FCC experience than the staff perceptions of providing FCC warrants investigation. Further exploration is also recommended to understand reasons for the low rating by both groups in the area of support or emotional care of the family.

Acknowledgements and Conflicts of Interest

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