

ARTICLE

Measuring Family Centred Care: Working with Children and Their Parents in a Tertiary Hospital

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Abstract

Rationale and aim: Family-centred care (FCC) is widely used in paediatrics, though no rigorous evidence for it exists. A growing body of qualitative research raises concerns about FCC, and health professionals' attitudes to it. We measured attitudes to working with children and working with parents of hospitalised children held by nurses, doctors, allied health and ancillary staff at an Australian children's hospital, using a validated questionnaire with two scores, one for working with children, one for working with parents, and demographic characteristics, and compared responses.

Method: we recruited a randomized sample, and compared means of working with children and working with parents scores, using a Wilcoxon signed rank test $p < 0.0001$. Mean differences by categories of demographics were estimated using ANOVA and median test compared the median scores.

Results: respondents gave significantly more positive scores for working with children than parents. These were influenced by level of education, whether respondents were parents themselves, if they held senior positions, had worked with children for a long time, and held a paediatric qualification.

Conclusions: paediatric health professionals view working with children in a more positive light than working with parents. However, if FCC was being implemented effectively, given its emphasis on the whole family as the unit of care, there would be no difference between working with children or their parents. This quantitative study supports the increasing body of qualitative research which highlights problems with this model. In addition, this study provides a way to measure FCC.

Keywords

Children, family-centered care, parents, tertiary hospital

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Introduction

Paediatric health services world wide use family-centred care (FCC) as a model around which to plan and implement care. "Family-centred care 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 recognized as care recipients" [1]. Its main element is the involvement of the parents in a child's care. The Institute of Patient and Family Centered Care [2] in the United States (US) believes it is highly successful, and lists elements of which it consists, namely recognizing the family as a constant in the child's life; facilitating parent-professional collaboration at all levels of health care;

honouring the racial, ethnic, cultural, and socio-economic diversity of families; recognizing family strengths and individuality and respecting different methods of coping; sharing complete and unbiased information with families on a continuous basis; encouraging and facilitating family-to-family support and networking; responding to child and family developmental needs as part of health care practices; adopting policies and practices that provide families with emotional and financial support; and designing health care that is flexible, culturally competent, and responsive to family needs.

While it is said to be widely used, Darbyshire [3] suggested that FCC is a wonderful ideal but in reality, difficult to implement because of the judgemental attitudes of nurses towards parents, resulting in the feeling that they are “parenting in public”. Likewise, nurses feel they are “nursing in public”. He suggested that for FCC to succeed, understanding, empathetic communication between parents and nurses was necessary.

While FCC is expressed in many policy documents in paediatric health facilities as an integral part of their philosophies, there is little evidence that FCC works, is effective, or has much impact on the delivery of care [4]. While there is no rigorous evidence that FCC works, or makes a difference to children, parents or staff, there is a growing body of qualitative research which shows consistent themes when explaining the problems with implementation of FCC [5]. These include health professionals acting as gatekeepers to parental access to admitted children [6], the use of punishment and reward if the parents do, or do not, fit the health professionals’ perceptions of acceptable behaviour [7], parents’ use of strategies such as bargaining with staff to ensure their needs are met [8], and exclusion of parents at the whim of the health professional [9].

Previous studies [10,11] using the technique employed here found significant differences between staff’s feelings about working with children and working with parents. All subject groups gave a more positive score for children than parents. While this is not surprising, given that people may choose to work in paediatrics because they enjoy working with children, it is not congruent with a FCC policy, in which the children and parents are to be treated as a single, integral unit. The aim of this current study was to determine attitudes to working with children and working with parents of hospitalised children held by staff-nurses, doctors, allied health and ancillary – at an acute care, tertiary referral, public hospital, where care is free at point of delivery and paid for through universal taxation, and which espouses a policy of family-centred care. .

METHODS

Tool

The tool used was the “Working with Families” questionnaire, which has been trialed in Australia, the UK,

Indonesia and Thailand [10]. It contains a range of demographic questions, plus two questions: “I find working with children ...” and “I find working with parents of children ...” It includes a scoring system using semantic differentials [12]. There are 10 scales each of which contains at one end an adjective and at the other its antonym. Subjects placed a cross on the line which best met how they felt about each adjective. (The adjectives were first derived from literature, interviews and trials) [11,13]. In trials, the scoring system consistently gained Cronbach’s alpha scores of 0.8 and above. Also included was an example on how to complete the questions. The poles of the questions were changed to ensure that respondents had to make a judgement about each adjective set, in other words, some score lines went from positive to negative, while others were reversed. The only problem encountered with the questionnaires were 10 subjects who, on the first round, completed only one side of the sheet. Once this was encountered, we added a line to the bottom of each page reminding subjects to complete the other side.

Sample size, recruitment and data collection

Ethical approval was given by Curtin University Human Research Ethics Committee (HR 93/2009), plus the relevant hospital’s Human Research Ethics Committee.

Using random stratified sampling from the total population of hospital staff, with a computed confidence level of 95%, an estimated power of 90%, and a possible non-return rate of 50%, the required sample was determined to be 23 doctors, 54 nurses, 26 allied health and 44 ancillary (administration and domestic) staff. Recruitment was through the hospital internal mail, with four mail-outs of questionnaire, information sheet and return envelope, to achieve the required numbers. Consent was implied by return of the anonymous questionnaire. A response rate of 60% yielded responses from 32 doctors, 72 nurses, 39 allied health professionals and 67 ancillary staff. Towards the end of the data collection period, to meet the required number, we had to attend meetings to hand deliver and collect questionnaires, and this yielded approximately 10% of the responses. They all remained anonymous, but this may have limited the generalizability of the findings to some degree. Data were entered into SPSS as the questionnaires arrived.

Data analysis

Demographic characteristics of subjects are presented in numbers and percentages (Table 1). We conducted an exploratory analysis of the outcome variables to examine their distribution. Both outcomes – working with children and working with parents – were not normally distributed, although the scores for working with children approximated normal. For the simplicity of presentation and understanding we have presented both mean and

median values of these outcomes by background characteristics. To compare the overall mean difference between working with children and working with parents scores, we used a non-parametric sign test (Wilcoxon signed rank test $p < 0.0001$). The mean differences by categories of background characteristics were estimated using ANOVA. Median test was used to compare the median scores of the two questions “Most of the time, I find working with children ... (score)” and “Most of the time, I find working with parents of children ... (score)”

Results

Characteristics of the sample

Table 1: demographic characteristics of subjects

	N(%)	
Gender	Male	22 (12.8)
	Female	150 (78.2)*
Age group	18-25 years	11 (5.8)
	26-35 years	40 (21.1)
	36-45 years	63 (30.5)
	Over 45 years	96 (42.6)
Education level	High school	16 (8.4)
	Certificate level	22 (11.6)
	Diploma	34 (17.9)
	Undergraduate	41 (21.6)
	Postgraduate university	77 (40.5)
Marital status	Not married	40 (21.1)
	Married/defacto	129 (67.9)
	Widowed/divorced	21 (11.1)
Own children	0	60 (31.6)
	1-2	91 (47.0)
	More than 2	39 (20.5)
Occupation	Nurse	66 (34.7)
	Doctor	31 (16.3)
	Allied health	36 (18.9)
	Ancillary staff	57 (30)
Years in occupation	Under 1 year	6 (3.2)
	1-5 years	34 (17.9)
	6-10 years	28 (14.7)
Level	over 10 years	122 (64.2)
	Senior	153 (80.5)
Years in current position	Junior	57 (19.5)
	Under 1 year	20 (10.5)
	1-5 years	86 (45.3)
	6-10 years	31 (16.3)
Years working with children	over 10 years	53 (27.9)
	Under 1 year	7 (3.7)
	1-5 years	39 (20.5)
	6-10 years	37 (19.5)
Paediatric qualification	over 10 years	107 (56.3)
	Yes	95 (50)
	No	95 (50)

*this question was left blank by 18 subjects

Missing data precluded the use of 20 questionnaires, leaving 190 for analysis. The sample was congruent with the characteristics of the health workforce in many developed countries. Table 1 shows that almost three-quarters were over 36 years of age, 62% had university education, and another 40% had postgraduate qualifications. About 80% had partners, or had been divorced or widowed, and 68% were parents themselves. Nurses comprised 35% of the subjects, 16% were doctors, 19% allied health professionals, and 30% ancillary staff, and over 80% had been in those occupations for longer than five years. Forty-four percent of the sample had held their current position for over five years, and 76% had been working with children for more than five years. A high percentage (80%) was in junior positions, and half of the subjects had a specialist paediatric qualification of some kind. Men comprised 13% of the sample, though for an unknown reason, this one question was not answered by 18 people.

Comparison of scores for working with children and working with parents

Comparison of the two scoring questions produced significantly different results (the mean score for working with children was 4.3 (SD=0.57), and with parents 3.8 (SD = 0.66). As the scoring system was set up, the highest (and most positive) score possible was a 5, while the lowest (and least positive) was 1. Consequently, these results show that the subjects gave a more positive score for working with children than for working with their parents.

We examined influences of sample characteristics on the scores (Table 2). Age group, marital status, years in occupation, years in present position, and gender had no influence on differences between mean or median scores. However, several were statistically significant. Those with higher levels of education gave a significantly more positive score for both working with children and working with parents ($p < 0.001$). People who had over two children themselves gave a more positive score for working with both children ($p = 0.028$) and parents ($p = 0.027$) than those who had fewer children, or none. A person in a senior position was more likely to give a higher score for working with children than more junior staff ($p = 0.014$) but there was no difference between senior and junior staff's scores for working with parents. Those who had worked with children for a long time gave more positive scores for working with parents than those who had not been working with children for long ($p = 0.01$), but there was no difference between them for the working with children score. Staff who held a paediatric qualification gave a higher score for working with both children ($p < 0.01$) and parents ($p = 0.001$) than those who did not have a paediatric qualification (Respondents were not required to list their specialist qualifications, but they were, in the main, postgraduate study, either postgraduate certificates, diplomas, Master or Doctor of Philosophy degrees from

Table 2: Mean and median scores for (a) working with children and (b) working with parents, by demographic characteristics

			(a) children		(b) parents	
	N	%	Mean*	Median**	Mean*	Median**
Overall	190	100	4.3	4.4	3.8	3.8
Age group						
18-25	11	5.8	3.9	4.0	3.5	3.2
26-35	39	20.6	4.3	4.5	3.6	3.7
36-45	58	30.7	4.4	4.6	3.8	3.9
>45	81	42.9	4.3	4.4	3.9	3.9
<i>p-value</i>			0.096	0.075	0.0235	0.234
Educational level						
2	16	8.6	4.0	4.2	3.4	3.1
3	22	11.8	4.0	4.2	3.4	3.3
4	34	18.2	4.0	4.2	3.8	3.9
5	40	21.4	4.5	4.6	3.9	3.9
6	75	40.1	4.5	4.5		
<i>p-value</i>			<0.001	0.0697	<0.001	<0.001
Marital status						
Not married	34	18.5	4.3	4.4	3.6	3.7
Married/de facto	129	70.1	4.3	4.5	3.8	3.9
Widowed/divorced	21	11.4	4.0	4.1	3.6	3.6
<i>p-value</i>			0.236	0.054	0.1825	0.2581
Number of own children						
none	60	31.6	4.1	4.3	3.6	3.7
1-2	91	47.9	4.4	4.5	3.8	3.9
>2	39	20.5	4.4	4.6	3.9	4
<i>p-value</i>			0.028	0.093	0.027	0.091
Years in occupation						
1	40	21.2	4.2	4.3	3.5	3.7
2	28	14.8	4.4	4.6	3.7	3.9
3	121	64.0	4.4	4.5	3.9	3.9
<i>p-value</i>			0.135	0.089	0.035	0.279
Seniority						
senior	149	80.5	4.4	4.5	3.8	3.8
junior	36	19.5	4.1	4.1	3.7	3.8
<i>p-value</i>			0.014	0.021	0.394	0.827
Years in present position						
< 1yr	20	10.5	4.3	4.2	3.8	3.9
1-5 yrs	86	45.3	4.3	4.5	3.7	3.9
6-10yrs	31	16.3	4.4	4.5	3.9	3.8
> 10yrs	53	27.9	4.3	4.4	3.8	3.8
<i>p-value</i>			0.669	0.304	0.552	0.813
Years working with children						
< 1yr	7	3.7	4.1	4	3.6	3.6
1-5 yrs	38	20.1	4.1	4.3	3.5	3.5
6-10 yrs	37	19.6	4.4	4.5	3.8	3.9
> 10yrs	107	56.6	4.4	4.5	3.9	3.9
<i>p-value</i>			0.068	0.293	0.01	0.057
Paediatric qualification						
Yes	92	49.2	4.5	4.5	3.9	3.9
No	95	50.8	4.2	4.2	3.6	3.7
<i>p-value</i>			<0.001	0.005	0.001	3.7
Sex						
male	25	14.0	4.4	4.4	3.8	3.9
female	153	86.0	4.3	4.4	3.7	3.8
<i>p-value</i>			0.236	0.682	0.687	0.333

Note: mean and median difference between (a) child and (b) parent are statistically significant (all p-values<0.05, using non-parametric mean and median tests)
 * p-value to examine the mean differences by categories of background characteristics are estimated using the ANOVA (although ((b) parent does not follow normality assumption but (a) child is close to)

**p-value to examine the significant difference of the median values are calculated using the non-parametric medium test

across the span of nursing and allied health – a requirement for specialisation in Australia, or fellowship qualifications for doctors).

Discussion

Family-centred care is ubiquitous in policy documents in paediatric health services, and while evidence about its effectiveness is either questionable, or not available, good qualitative studies [3, 5-9] raise consistent concerns about its implementation and effectiveness. At its core is the idea of the family as the single unit of care, regardless of how that family is described, and care has to be planned around the whole family, rather than the individual sick child [1]. Effective communication is the key to FCC, and this requires trust between family members and the staff caring for them and their child [15-17]. Trust requires positive regard and respect on both sides, however, if health professionals like working with only one part of the unit to which they are giving care, then that respect and regard can be jeopardised. Our findings indicate that this group of health professionals, similarly to others where this tool has been used [10,11] give a more positive score for working with children than they do for working with their parents. While some might argue that this is natural given that people may choose to work in paediatrics because they like children, it brings into question the whole premise of FCC. If FCC was truly being implemented, then there would be no significant difference between the scores for both children and their parents. A unity of care for the family cannot be achieved if one group is preferred over the other, and consequently FCC is not functioning as it should.

It is unsurprising that staff who were older, had children of their own, and held a specialist qualification in paediatrics gave higher scores for both working with children and with parents than those who were younger, did not have children and were not specialist educated. What is somewhat perplexing is the lower score for working with children given by those in senior positions in contrast to those who were junior, without a difference in working with parents' scores. Perhaps more senior staff relate better to adults than children, or have lost some of their enthusiasm for working with children. This could perhaps be teased out with qualitative methods of inquiry. However, the more positive scores for working with parents given by those who have worked in paediatrics for a long time versus their less experienced colleagues suggests that understanding of parents and the effects on their lives of a child's hospitalization is something that grows over time and with exposure.

This quantitative study contributes to the growing body of evidence that suggests problems with FCC as a model of care, and that Darbyshire may be right – that FCC is a wonderful ideal but may not be possible in practice. It is time to question the ethics [18] of continuing to implement a model that may not work.

Limitations

One question about gender was not answered by 18 people (though we do not know why). Ten other questionnaires were not included because of missing data. To reach the required sample size, we had to personally recruit subjects, and while the questionnaires remained anonymous, this may have affected the generalizability of the findings in this population. Return of the questionnaires lagged towards the end of the data collection period and we had to resort to attending sessions such as grand rounds and handing out the questionnaires. This pertained to less than 10% of the sample, but may have biased our results.

We have included a tertiary specialist paediatric health service only. Further work is underway in second level hospitals, and also in rural and remote area services. If we concatenate the data and increase the sample size, we will be better able to investigate the differences between the sub-groups, for example, between the different health professionals, thereby gaining not just a deep understanding of how different approaches and education address issues around FCC as a care delivery model, but also will provide evidence on which we can tailor education packages for each group.

Implications for research

1. Further quantitative examination of FCC should be undertaken to prove (or disprove) its effectiveness as a model of care⁴.
2. This study shows problems with FCC in an acute care tertiary paediatric hospital, but children are cared for in a wide range of settings. The study is being repeated in two secondary hospitals and two rural hospitals at present, and could be undertaken in a variety of settings, for example, community health.
3. Research is needed to develop, implement and trial an alternative model of care.

Implications for practice

One must query the ethics of continuing a model of care that is of doubtful efficacy, for which little rigorous evidence exists, and which is more and more being challenged by the findings from solid qualitative research. A large amount of funding is used to support a model that may not be working and may not be the best way of delivering care. An alternative approach is urgently needed.

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