Research

Perceptions of working with children and their parents in a rural health setting in Australia

Abstract

Background There has been discussion in the literature regarding family-centred care and whether it is being utilised in the manner in which it is intended, or if it is idealistic and difficult to implement in practice. This paper examines perceptions about caring for children and their parents – the cornerstone of family-centred care – of health professionals working with children and working with their families in rural community settings.

Methods The tool was a widely, internationally used questionnaire Working with Families, consisting of demographic questions and two questions that explore participants' perceptions of working with children and their parents. Participants were health professionals working in child and family health services within a rural health service in New South Wales, Australia. Invitations and information were emailed, and consent implied by completion of Working with Families.

Findings In 2018, 57 participants responded, with over half identifying as registered nurses; the remainder were allied health professionals. No doctors chosse to participate in the survey. The majority were female, and 94% had been in their community role working with children and families for at least 5 years. The overall finding was that health professionals rate working with children higher than working with their parents – mean difference 0.36 (95% CI:0.24, 0.48; p<0.001).

Conclusion This study found that health professionals gave a statistically significant more positive score for working with children than with their parents. This adds to the argument that family-centred care as a way to care for children when they access health services is problematic. The conclusions support the argument that it is time to review family-centred care and trial a new model, child-centred care, in health situations.

Keywords Family-centred care, rural health, community health, health professionals, community nursing

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What is already known about the topic

- Health professionals need to hear the voice of children and their families.
- Family-centred care has been established as a model for care with children and families since the 1980s.
- A series of research studies in various settings has identified that health professionals who work with children prefer working with children than working with their parents.

What this paper adds

- Findings support the emerging evidence that health professionals working with children in various settings and countries give a higher score for working with the children to working with their parents.
- It is time to consider a different model of care, where the child is at the centre.

Introduction

This brief paper continues examination of family-centred care using a simple, effective questionnaire for health professionals who work with children and families which tests their perceptions of working with children and working with their parents. Several papers have been published in this series, in acute care, community care, rural and remote health services and in different countries. All demonstrate that, statistically, health professionals give a more positive score for working with children than with parents.[1–8]

We are being asked to question family-centred care[9] which, while ubiquitous in theory in children's health services, in practice is fraught with difficulty[10] and does not adequately capture the voice of the child. A new model, child-centred care[11,12], is being developed and tested. It holds that the child who is, after all, the reason for the encounter in the health service, is being overlooked as the unit of care. Theoretically, child-centred care strongly supports the presence of family members in a child's health encounter, but unless the child is the unit of care, the family's needs are likely to preclude the needs (and perceptions) of the child.

The aim of this current study is to test health professionals' perceptions of working with children and working with parents in a community setting within a large, rural health district in New South Wales (NSW), Australia.

Methods

Setting

The site included in this current research project was a rural NSW community child health setting in a large region covering 250,000 square kilometres, which is similar in size and practice to other such entities in larger regional districts across NSW. The proposed participants included allied health staff, nurses and doctors.

Data collection tool

A simple questionnaire, Working with Families, with questions about demographic characteristics and two other questions about working with children and working with their parents was developed in Australia.[8] It has since been used in specialist paediatric health facilities, second-level generalist hospitals where children are cared for, rural and remote facilities, emergency care, and community child health facilities. These sites are in Australia, the United Kingdom, the United States of America, Turkey, Indonesia and Thailand.[1-8] Working with Families is reliable and valid and, because of its simplicity, easy to complete and use. The two questions, "Most of the time, I find working with children..." and "Most of the time, I find working with parents of children..." consistently give a Cronbach's alpha score of above 0.8, and because there are only the two questions, other validity statistics are inappropriate. Semantic differentials[13] make calculation of the scores easy enough to be done by hand. Each question has ten adjectives and their antonyms at the end of a five-point scale, and the mean is calculated for each of the questions. Instructions are provided, with an example of how to complete the semantic differential questions.

Most of the time, I find working with children:

satisfying	__:__:__:__:__	aggravating
distressing	__:__:__:__:__	enjoyable
pleasurable	__:__:__:__:__	painful
fascinating	__:__:__:__:__	dull
stimulating	__:__:__:__:__	debilitating
boring	__:__:__:__:__	entertaining
comfortable	__:__:__:__:__	uncomfortable
pleasant	__:__:__:__:__	unpleasant
unrewarding	__:__:__:__:__	rewarding
agreeable	__:__:__:__:__	disagreeable

Most of the time, I find working with parents of children:

satisfying	__:__:__:__:__	aggravating
distressing	__:__:__:__:__	enjoyable
pleasurable	__:__:__:__:__	painful
fascinating	__:__:__:__:__	dull
stimulating	__:__:__:__:__	debilitating
boring	__:__:__:__:__	entertaining
comfortable	__:__:__:__:__	uncomfortable
pleasant	__:__:__:__:__	unpleasant
unrewarding	__:__:__:__:__	rewarding
agreeable	__:__:__:__:__	disagreeable

Figure 1. Working with Families: core questions

In 2018, we asked all doctors, nurses and allied health staff working within the local health district community child and family health services to participate. They received the introductory email with the information sheet via their managers, and a further email was sent 2 weeks later with the survey link. The survey links were sent to all the managers to distribute to the appropriate staff at two weekly intervals for 2 months. Consent was implied by engaging in the online survey. There were a total of 57 participants – 30 registered nurses, and 27 allied health workers; no doctors chose to participate.

A copy of the questionnaire is available on request; however, for illustration, the two perceptions questions are included in Figure 1, and the demographic characteristic questions are demonstrated in Table 1.

Ethics approval

Approval was given by the original human research ethics committee that approved many of the studies in the series (HREC/14/QTHS/38) and also the university which oversaw this particular study (CSU117003). In addition, health service

Table 1. Demographic characteristics of respondents

		n (%)
Gender (n=57)	Male	2 (3.51)
	Female	55 (96.49)
Age group (n=57)	18–25 years	4 (7.02)
	26–35 years	12 (21.05)
	36–45 years	14 (24.56)
	Over 45 years	27 (47.37)
Education level (n=57)	High school	3 (5.26)
	Certificate	7 (12.28)
	Diploma	18 (31.58)
	Undergraduate	29 (50.88)
	Postgraduate	–
Marital status (n=55)	Not married	10 (18.18)
	Married/de facto	44 (80.00)
	Widowed/divorced	1 (1.82)
Number of children (n=55)	None	18 (32.73)
	1–2 children	16 (29.09)
	>2 children	21 (38.18)
Hours to work (n=57)	<1 hour	53 (92.98)
	1–2 hours	4 (7.02)
Role (n=57)	Nurse*	30 (52.63)
	Medical officer	–
	Allied health professional	27 (47.37)
Years in occupation (n=57)	<1 year	3 (5.26)
	1–5 years	10 (17.54)
	6–10 years	2 (3.51)
	>10 years	42 (73.68)
Level of seniority (n=55)	Senior	43 (78.18)
	Junior	12 (21.82)
Years in current position (n=57)	<1 year	9 (15.79)
	1–5 years	22 (38.60)
	6–10 years	9 (15.79)
	>10 years	17 (29.82)
Years working with children (n=57)	<1 year	2 (3.51)
	1–5 years	12 (21.05)
	6–10 years	2 (3.51)
	>10 years	41 (71.93)
Paediatric qualification (n=56)	Yes	31 (55.36)
	No	25 (44.64)

**All were registered nurses*

ethics approval and research governance approval were given (GWAHS 2017-023, SSA/17/GWAHS/28).

Data analysis

Consistent with the other studies using this questionnaire[1–8] data were not normally distributed and so we used mean and median values, by demographic characteristics; p-value was set at <0.05. Non-parametric Wilcoxon signed rank test compared the overall mean difference between the scores for working with children and working with parents; ANOVA tested mean differences by demographic characteristics, and the median test was used to compare mean scores of the 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

Response rate

The information sheet and online questionnaire link were sent to all registered nurses, doctors (including paediatricians), and allied health staff working in community child health in the local health district. The managers of these staff distributed the information sheet and link to the online questionnaire to their staff. All remained anonymous to the research team. Consequently, we were not able to calculate a response rate. Fifty-seven participants responded, including 27 allied health staff, but we did not ask them to identify their specific profession. Thirty registered nurses responded, but no doctors.

Demographic characteristics of participants

Of the 57 participants, just over half were registered nurses, and the remainder were allied health professionals (Table 1). Most were female (96.5%), 67% had children of their own, 94% had been in their current roles for at least 5 years, while 78% held senior roles within the health service. More than half the responders held a paediatric qualification (55.4%).

Scores for working with children and working with parents

The mean overall score for working with children was 4.26 (95% CI:4.11, 4.42), for parents 3.91 (95% CI:3.73, 4.08). The mean difference between the two was 0.36 (95% CI:0.24, 0.48; p<0.001). The lower the score, the less positive the outcome (Table 2). Table 2 contains comparisons of the effects of the demographic characteristics on the scores. The mean and median scores for working with children, and working with parents, by participant demographic characteristics are provided. The only statistically significant factor between the two groups is whether or not the participant had a specialist paediatric qualification (p=0.018, 0.025, 0.01, 0.31). The mean score for working with children was higher than that for working with their parents.

Discussion

This study supports all the other studies in this series, giving similar results and thereby contributing to the argument that, as proposed by Darbyshire over 30 years ago, while family-centred care is a wonderful ideal, it is very difficult to

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

		Children (n=52)		Parents (n=53)	
		Mean*	Median**	Mean*	Median**
Overall		4.26	4.20	3.91	3.90
	p-value	*<0.001*		*<0.001*	
Age group (years)	18–35 years	4.16	4.00	3.74	3.60
	36–45 years	4.27	4.25	3.79	3.9
	>45 years	4.31	4.50	4.07	4.05
	p-value	*0.703*	*0.352*	*0.213*	*0.560*
Education level	High school / certificate	4.43	4.62	4.15	4.16
	Diploma	4.16	4.00	3.79	3.90
	Undergraduate	4.26	4.21	3.88	3.80
	p-value	*0.469*	*0.217*	*0.353*	*0.560*
Marital status	Not married / widowed / divorced	4.21	4.05	3.87	4.07
	Married / de facto	4.28	4.26	3.93	3.90
	p-value	*0.749*	*0.482*	*0.799*	*0.575*
Number of children	None	4.17	4.00	3.72	3.67
	1–2	4.40	4.56	4.09	3.83
	>2	*4.25*	*4.50*	*3.96*	*3.90*
	p-value	*0.509*	*0.321*	*0.235*	*0.999*
Role	Nurse	4.29	4.00	4.02	3.90
	Allied health professional	4.22	4.30	3.78	3.90
	p-value	*0.695*	*0.250*	*0.184*	*0.983*
Years in occupation	≤5 years	4.16		3.64	3.40
	6+ years	4.29		3.98	3.90
	p-value	*0.478*		*0.096*	*0.980*
Level	Senior	4.20	4.28	3.93	3.90
	Junior	4.18	4.00	3.80	3.60
	p-value	*0.604*	*0.253*	*0.535*	*0.763*
Years in current position	Under 1 year	3.98	3.94	3.46	3.38
	1–5 years	4.26	4.20	3.91	3.95
	6–10 years	4.06	4.00	3.75	3.75
	Over 10 years	4.49	4.67	4.19	4.11
	p-value	*0.103*	*0.057*	*0.038*	*0.356*
Years working with children	≤5 years	4.26	4.20	3.83	4.00
	6+ years	4.26	4.25	3.93	3.90
	p-value	*0.992*	*0.938*	*0.624*	*0.748*
Paediatric qualification	Yes	4.42	4.60	4.11	4.11
	No	4.06	4.00	3.66	3.67
	p-value	*0.018*	*0.025*	*0.010*	*0.031*

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 median test*

implement effectively in practice.[10] Our conclusions support the argument that it is time to review family-centred care and trial child-centred care in health situations where children are cared for.

As with the other studies[1–8], the significant difference between working with children and working with parents indicates that, in this group of health professionals, they give more positive scores for working with children over working with parents. And, similarly to all the other studies in this work, we argue that this indicates that family-centred care is hugely problematic. As with all the studies using this supposition implied in the Working with Families questionnaire[1–8], assumptions are held about its application to the family-centred care model. Of course, family-centred care is and has been tested, though our systematic reviews for both the Cochrane Collaboration[9] and the Joanna Briggs Institute[14,15] demonstrate that family-centred care has never been rigorously tested. A large, international collaboration led by Professor Anna Axelin in Finland (https://www.utu.fi/en/people/anna-axelin) has translated another questionnaire – the Shields and Tanner Questionnaire[21] about perceptions regarding family-centred care held by both health professionals and parents of admitted children – into 15 languages, and it has been, or is being, applied in as many countries. A more detailed questionnaire than Working with Families, it is giving some insights into how and why family-centred care may be problematic. Importantly, this work will provide a large, coordinated database from which assumptions can be tested.

The only significant influence, that of holding a paediatric qualification, may indicate that there is something in that education that is problematic. Perhaps the idea of parental/family involvement is not taught appropriately. We found this with some of the other studies, and it is hard to explain. This finding needs more exploration, probably with qualitative research.

Family-centred care is based on the idea that when a child comes into a health service, the family is the unit of care, and so, if family-centred care is working effectively, there should not be a difference between how health professionals perceive working with children and working with their parents. Until this discrepancy is eliminated, family-centred care cannot work.[16] It is time for a rethink, and this is occurring.

Clinicians and researchers in the paediatric and child health world are developing a new theory that will have much application. Child-centred care, first discussed in 2014 by Carter and Ford[11], is now being examined, tested and argued about by many others[17–19] via an international collaboration that is bearing fruit. Its proponents argue that, theoretically at this stage, while family-centred care has been the model used in health services across the world since the 1970s–80s, it is flawed[20] because if the focus is on the family members, then the child's voice is not always heard, and the child is the reason for the admission and so should be the centre of the care delivery model.[11,12] This is not to say the family or parents/carers should be excluded – of course, they are integral to the child's care, but if the child is being lost in the interactions, thinking and actions that are taking place, then it makes little sense. We urge interested readers to 'watch this space' as this new model emerges and is tested and subsequently applied in the care of children who need care from health services.

Limitations

The study was one rural setting, with its unique environment and issues particular to its setting, including accessibility of services and the need to recruit appropriately qualified staff. The convenience samples, as with all the other studies in the series, pose limitations for the findings. While the other studies in the series[1–8] give similar results, we decided to continue this into another rural setting to enhance applicability across various healthcare settings. Unfortunately, no medical officers responded. It was not possible to determine the response rate, as it was distributed and collated solely by the health district staff, who did not keep a record of this. We did not access the online platform until the close of the survey.

Conclusion

A part of a series, this paper uses the same tried and tested questionnaire as used in others in the set which tests how health professionals who work with children perceive working with children and working with their parents. After gaining relevant ethics approval, it was applied with participants from a healthcare setting in rural NSW, Australia.

Consistent with the findings of all the studies in this series, we found that health professionals gave a statistically significant more positive score for working with children than with their parents. This adds to our argument that family-centred care as a way to care for children when they access health services is flawed. A new model, child-centred care, is emerging. Using this model, the focus during a health service encounter will be the child's voice rather than the voices of family members.

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Conflict of interest

The authors declare no conflicts of interest.

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Ethical approval

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References

1. Smyth W, AlMamun A, Shields L. Multidisciplinary perceptions of working with children and their parents in rural and remote Australian hospitals. Nord J Nurs Res 2019;39(4):226–32. doi:10.1177/2057158519881745
2. Shields L, Smyth W, AlMamun A, Lucas L. Working with families in an emergency department: perceptions of working with children and their parents. Eur J Pers Cent Healthc 2018;6(2):189–95.
3. Smyth W, Kruze R, AlMamun A, White A, Shields L. Working with families in community services: multi-disciplinary perceptions of working with children and their parents. Neonatal, Paediatric and

Child Health Nursing 2016;19(1):19–23.

4. Shields L, Çavuşoğlu H, Pars H, Mamun AA. Measuring family centred care: working with children and their parents in a Turkish hospital. Eur J Pers Cent Healthc 2015;3:327–333.
5. Shields L, Mamun AA, Flood K, Combs S. Measuring family-centred care: working with children and their parents in two second level hospitals in Australia. Eur J Pers Cent Healthc 2014;2(2):206–211.
6. Aggarwal S, Chadha P, Kalia S, Richardson S, Winterbottom L, Shields L. Perceptions of family-centred care: a UK pilot study of the Shields and Tanner questionnaires. Neonatal, Paediatric and Child Health Nursing 2009;12(2):25–29.
7. Shields L, Mamun A, Pereira S, O'Nions P, Chaney G. Measuring family centred care: working with children and their parents in a tertiary hospital. Int J Pers Cent Med 2011;1(1):155–60.
8. Shields L. A comparative study of the care of hospitalized children in developed and developing countries [PhD thesis]. Brisbane (Australia): University of Queensland; 1999.
9. Shields L, Zhou H, Pratt J, Taylor M, Hunter J, Pascoe E. Family-centred care for hospitalised children aged 0–12 years. Cochrane Database Syst Rev (update) 2012;10. Art. No: CD004811. doi:10.1002/14651858.CD004811.pub3
10. Darbyshire P. Living with a sick child in hospital: the experiences of parents and nurses. London: Chapman & Hall; 1994.
11. Carter B, Bray L, Dickinson A, et al. Child-centred nursing: promoting critical thinking. London: SAGE; 2014.
12. Coyne I, Hallstrom I, Soderback M. Reframing the focus from a family-centred to a child-centred care approach for children's healthcare. J Child Health Care 2016;20:494–502.
13. Osgood CE, Suci GJ, Tannenbaum PH. The measurement of meaning. Urbana: University of Illinois Press; 1957.
14. Watts R, Zhou H, Shields L, Taylor M, Munns A, Ngune I. Family-centred care for hospitalised children aged 0-12 years: a systematic review of qualitative studies. JBI Libr Syst Rev 2014;10(14):3917–35. doi:10.11124/jbisrir-2014-1683
15. Shields L, Zhou J, Taylor M, Hunter J, Munns A, Watts R. Family-centred care for hospitalized children aged 0–12 years: a systematic review of quasi-experimental studies. JBI Database System Rev Implement Rep 2012;10(39):2559-2592. doi:10.11124/jbisrir-2012–32.
16. Uniacke S, Kayali-Browne T, Shields L. How should we understand family-centred care? J Child Health Care 2018;22(3):460–469. doi:10.1177/1367493517753083
17. Smith J, Shields L, Neill S, Darbyshire P. Losing the child's voice and 'the captive mother': an inevitable legacy of family-centred care? Evidence Based Nursing Online First 2017. doi:10.1136/eb-2017-102700.
18. Al-Motleq M, Carter B, Neill S, Kristensson-Hallstrom I, Foster M, Coyne I, et al. Toward developing consensus on family-centred care: an international descriptive study and discussion. J Child Health Care 2019;23(3):458–467.
19. Phiri PGMC, Chan CWH, Wong CL. The scope of family-centred care practices, and the facilitators and barriers to implementation of family-centred care for hospitalised children and their families in developing countries: an integrative review. J Pediatr Nurs 2020;55:10–28. doi:10.1016/j.pedn.2020.05.018.
20. Foster M, Shields L. Bridging the child and family centered care gap: therapeutic conversations with children and families. Comp Child Adolesc Nurs 2020;43(2):151–158. doi:10.1080/24694193.2018.1559257.
21. Shields L, Tanner A. Pilot study of a tool to investigate perceptions of family-centred care in different care settings. Pediatr Nurs 2004;30(3):189–197.