

GUEST EDITORIAL

What is “family-centered care”?

Linda Shields MD PhD FACN

Professor of Nursing - Tropical Health, College of Healthcare Science, James Cook University and Townsville Hospital Health Service, Townsville and Honorary Professor, School of Medicine, The University of Queensland, Brisbane, Queensland, Australia

Keywords

Child-centered care, family-centered care, implementation, health professionals, measurement, paediatrics, person-centered healthcare

Correspondence address

Professor Linda Shields, Tropical Health Research Unit, 1st Floor, Townsville Hospital, Townsville, Queensland 4810, Australia. E-mail: linda.shields@jcu.edu.au

Accepted for publication: 18 February 2015

Introduction

Family-centred care is a ubiquitous term in paediatric health facilities. It means that an admitted child can never be treated as a single individual patient and that the family is the unit of care, as the parents and family are central to the child's wellbeing, especially during traumatic experiences. There is no rigorous evidence that family-centred care works, but qualitative research is drawing out some grave concerns with how it is implemented. Part of the problem is that there are many descriptions of family-centred care, but few definitions and some of its component parts may be in place in some health services without the whole model being in place. This causes confusion amongst health professionals and parents and children and makes it impossible to test in a randomised controlled trial.

Visit any children's health facility anywhere - rich countries, poor ones; tertiary paediatric facilities, community child health services, institutions for children with disabilities - and one will find that they say they practise family-centred care. It may be in mission statements, clinical practice guidelines, leaflets for parents, signs on walls, policy documents - in other words, everywhere. “Family-centred care” sounds good; it sounds like something to which every health institution which cares for children should definitely use and sounds like a wonderful and ideal way to care for children who need healthcare. After all, every child has a family and every family is affected when a child is ill.

There is a wealth of literature about family-centred care, far too much to include here, or even in a single systematic review. Much research has been conducted on it, while many have tried to test it and its application in healthcare. It has been approached from many angles - the children's, the parents', the nurses', the doctors', the allied health professionals' and from health service managers'

perceptions. Sociologists have had a go, as have historians, philosophers, anthropologists, just about everyone. But what is it? And what does it mean for those on the receiving end, the families? Does it matter? Does it make a difference? Can we test it? Is there an alternative? In this paper I attempt to answer these questions and consider another model - that of child-centered care.

Does FCC work?

There is no solid evidence that family-centred care works, or if it makes a difference. As lead author on a Cochrane review about it (updated in 2012 and imminently to be updated again) [1,2], I can say this. Our team decided that we needed to see if this thing that was so widely applied in health services in many countries really was worth the amount of effort that was invested in telling everyone that it was being used. We decided to restrict our review to randomised controlled trials (RCT) only, as only such research could prove or disprove if family-centred care worked or not. Fortunately for us, we found a well-tested and validated tool to measure the family-centredness of studies [3] and employed in addition the standard Cochrane tools for quality assessment [4]. Over both the initial review and its update, we found only one study which could be included [5] and so could draw no real conclusions about its effectiveness.

Next, we decided to cast our net more widely and so undertook a separate review of quasi-experimental studies of family-centred care, through the Joanna Briggs Institute (JBI) [6]. We used the same tool for family-centredness [3] and the quality assessment laid down by JBI [7]. We found none that met our criteria. One tool which kept cropping up, particularly in the medical literature, was the MPOC - the “Measuring Processes of Care” questionnaire [8]. Designed for use in disability services, MPOC has been

used in many medical specialities to test family-centred care. When we examined these studies and the MPOC, we did not include this tool because it was not measuring family-centred care, it measured what its name says - processes of care delivery.

From our clinical practice and as we trawled the literature, we knew that there was a growing body of qualitative research on this topic and so we set up another JBI review assessing qualitative studies only [9]. We used the same tool for family-centredness [3] and JBI's tools for assessing the quality of these types of studies [7]. This time we were more successful, but the final results were concerning (although confirming what we knew clinically). Of the 14 included studies, common themes included the value of parents being with their child and continuation of the parenting role while a child was an inpatient. However, there were more negative findings than positive, with barriers to parental involvement, problems with communication between parents and health staff and difficulties with role negotiation for parents and those caring for the child. Qualitative research cannot prove or disprove if something is working, or effective. Nonetheless, it provides insight into the concept under study and, in this case, demonstrated very effectively that there are grave concerns to be had about this thing we call "family-centred care".

Problems in the study and implementation of FCC

But why is family-centred care so difficult to study and so problematic to implement effectively? One of the reasons is possibly that no-one can really define what it is. Family-centred care evolved from the work of Anna Freud and Dorothy Burlingham [10], John Bowlby, James Robertson [11], Renee Spitz [12] and the governmental committees set up in the 1950s in the United Kingdom (UK) [13] and the United States of America (USA) [14] who revolutionised the care of children in hospital. Lobby groups of parents arose which further promoted what evolved into family-centred care and from these grew various organisations interested in the welfare of children admitted to hospital (discussed later).

While these all worked towards the wellbeing of children in health services, the term "family-centred care" seems first to have been codified in 1992 by the current Institute for Patient and Family-centered Care in the USA. It described the elements of family-centred care as primarily "Recognising the family as a constant in the child's life" and "Facilitating parent-professional collaboration at all levels of healthcare", amongst others [15]. These tenets are incontrovertible, but implementation of family-centred care has always been problematic. Darbyshire in 1994 [16] suggested it was a wonderful ideal, but very difficult to implement effectively because of the tensions in communication that seem to be an inevitable occurrence in parent - health professional interactions.

Defining FCC

Family-centred care, then, has proven difficult to define. Our review team made an attempt: "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" [17]. In a concept analysis of family-centred care [18], Mikkleson described family-centred care as "a partially mature and highly abstract concept" [18] and defined it thus: "the professional support of the child and the family through a process of involvement and participation, underpinned by empowerment and negotiation. Family-centred care is characterized by a relationship between healthcare professionals and the family, in which both parts engage in sharing the responsibility for the child's healthcare" [18].

These definitions are important, but we are still left with the question - yes, but what is it? Why is it so difficult to implement and measure? We need to think about what family-centred care means for those for whom it is designed - children and their parents and the staff who care for them. If the family is the central tenet in the child's life, then health services need to make provision for them.

An ideal model of FCC?

If I was given millions of dollars to design a truly family-centred hospital, I would include the following:

Structural aspects

Beds would be needed for parents who want to stay. These do not have to be in private rooms, in fact research suggests that children are best nursed with other children [19] (unless clinically contra-indicated). Parents staying overnight with their children need better than a recliner chair beside the bed. They need bathrooms, laundries and places to keep their belongings; for example, in cupboards close to the child's bed.

Places to eat and cheap and nutritious food would be required. As families often eat their meals together, there needs to be provision for this to happen. Accompanying family would need also to be fed. Café food is expensive and often not as nutritious as that available at home and if a parent has to leave a child's bedside to find food, then the child may be disadvantaged. Parents staying with children often find themselves financially compromised, having to pay for expensive food and prolonged parking [20,21] and so free parking needs to be provided. School and play facilities are needed and also television and computer games (for both child and parent).

Education

Once the structures are in place, then education needs to be considered. All the health service staff - not just the health

professionals - need education about what family-centred care entails. So do parents and children, as there is little point in educating the health service staff but not ensuring that the expectations of children and parents are aligned with the expectations of those delivering care. When a family brings a child into a health service, they encounter nurses, doctors and allied health professionals and alongside them are the administrative and professional staff who look after their paperwork (and are often the first people to whom they speak on admission and certainly on the telephone or electronically prior to admission). The domestic staff who deliver meals and clean the wards are often those with whom children and parents have many conversations, while the maintenance and gardening staff interact with families as they access outdoor areas of the facility. They, too, need education about family-centred care to make it work.

The expectations of children and families must match those in the health service. Education about family-centred care and what it means for them is vital if the process is to flow smoothly. A disconnect between what parents and children want, need and expect and what the health service can give them often causes confusion and conflict. Education for children and parents can be provided through hospital familiarisation schemes and clinics and by involving the media, newspapers and magazines through stories promoting family-centred care. Education programmes are required for schools, kindergartens and child care facilities. The most facilitative method of educating the general public about family-centred care is reported to be through judicious and planned use of social media - a dedicated website, Facebook, Twitter, *et cetera*.

Box 1 Websites of organisations which support family-centred care

- Australian Association for the Wellbeing of Children in Healthcare (AWCH) <http://www.awch.org.au/>
- Institute for Patient and Family-centered Care (USA) <http://www.ipfcc.org/>
- European Association for Sick Children <http://www.each-for-sick-children.org/>
- Action for Sick Children (UK) <http://www.actionforsickchildren.org.uk/>
- Children in Hospital Ireland <http://yoobyoo.ie/>

Family involvement

Organisations whose sole *raison d'être* is to promote and educate the general public about family-centred care exist in many countries (see Box 1). The Association for the Wellbeing of Children in Healthcare in Australia, the Institute for Patient and Family-centered Care in America, the European Association for Children in Hospital, Action for Sick Children in the United Kingdom, Children in Hospital Ireland, to name but a few, all provide valuable support for families, as well as extremely important policy development for documents such as charters of rights for

children, adolescents and families when they need healthcare. An essential role of such organisations is to provide avenues for family-to-family support and interaction, through direct contact with each other, blogs, newsletters and other means. It is imperative that these bodies need to be involved in the implementation of family-centred care in health services.

Communication skills and FCC

Philosophically, involvement of parents and children in their own care is critically important. This does not mean just asking them what they think or talking to parents and not to the children (of course, this is age-related). True partnership between health professionals and children and parents is at the core of successful implementation of family-centred care. The onus is on the health professional to put this in place and make it work, because the power gradient of any health service interaction sees the health professional at the top giving care to the patients/client/family below [22]. Hence, family-centred care will work only if the health professional can tailor all interactions to suit the contingencies and situations of the family, treatment, illness or condition and the health service at the time. An example is given in Box 2.

Box 2 An example of how communication can be geared to make it "family-centred"

Nellie is 4 years old and has cystic fibrosis (CF). Her mother, Tonia, like all CF parents, is very knowledgeable about the disease and understands only too well the impact it has on Nellie and the whole family. They live in a rural town and Nellie has been admitted to the local hospital's children's ward for a chest infection.

Anton is a nurse who works in the emergency department of the hospital and one night during Nellie's admission, the emergency department is quiet and the children's ward short staffed, so Anton is asked to work in the children's ward for his evening shift. Anton has little experience nursing children and has not seen a child with CF before. Nellie has been ordered a new antibiotic. Anton knows all about the drug, its pharmacological effects and before he gives Nellie her first dose, he checks the drug compendium to ensure he is well versed in the evidence around it. He goes to Nellie's bed.

Tonia missed seeing the doctor who ordered the antibiotic, so does not know that a drug which she knows little about, has been ordered. Anton has to explain. Tonia knows that Anton does not usually work in the children's ward and that he knows little about CF, so she is sceptical about Anton's ability to give effective care. However, Anton has to tell Tonia and Nellie about the new treatment.

In this situation, to make family-centred care work, the onus is on Anton to ensure his communication is geared to take into account Tonia's high level of knowledge about CF and about her daughter, while knowing that Tonia knows that he knows little about either. Anton, though, does know a lot about the new drug and needs to impart that knowledge to Tonia. For family-centred care to work successfully, Anton must work to create the partnership and good communication that makes family-centred care effective. He has to show Tonia and Nellie he respects their superior knowledge about CF, while respectfully educating them using his superior knowledge of the new antibiotic.

Misunderstanding of FCC

Family-centred care is often misunderstood, leading to Darbyshire’s [16] suggestion that family-centred care is an ideal way to care for children in health services, but is extremely difficult to implement effectively. Some health professionals believe it means the parents must stay with their hospitalised child and provide basic care [23]. Managers see this happening and believe that children’s wards may be overstaffed because the parents are present, then take staff to work in other areas of a busy hospital. The managers do not understand that the family-centred care model means that, in contrast to adult care, there is not just one individual patient. The unit of care, the family, may be several people and so *more* staff are needed [23]. The misconception that parents must stay abrogates the element of negotiation that is vital to effective family-centred care. Unless health professionals find out what else is happening in the life of a family, they cannot expect that a parent, who, for example, may have other sick children at home and no grandparents around to give support, should stay with their admitted child. True family-centred care means in-depth exploration of family situations and negotiation to determine the “best fit” for care of the admitted child [24].

A fallacy exists about family-centred care in poor countries. One hears comments about family-centred care being well implemented in developing countries because the family is always to be found at the child’s bedside [23]. In a poor country, this is most likely because patient to nurse ratios are so high that care cannot be given by the nurses and if the family did not stay, the child would receive no care at all (this is equally true in the case of adult care as well).

Box 3 Some of the problems of conducting a RCT of family-centred care

- Allocation of participants (families) to control or experimental groups would require several different hospitals to minimise contamination.
- This could be done through cluster randomisation. However, each hospital would have to be similar in all ways – management styles, models of care, demographics and so forth. Possibly the only country on earth with enough children’s hospitals run on similar lines, but geographically distant (to prevent contamination), would be the UK where all children’s hospitals are run along universal lines by the British National Health Service.
- A RCT as a single site study would be extremely difficult, if not impossible. In a town with one children’s hospital/ward/unit, an allocation to an experimental or control group would not be possible. Also, if a child comes to a particular hospital for particular care, then random allocation may not be appropriate. Places where a parent can choose where to take their child would also create confounders that would be impossible to overcome.
- Because family-centred care has been around for many years, it would be almost impossible to find hospitals where there would be no contamination.

Determining the evidence for FCC

So why is the evidence about family-centred care so hard to find? There have been forests of trees cut down to write papers, books and so forth, about it. The optimal way to determine if an intervention is effective or not is a RCT. To test family-centred care, a RCT would be horrendously expensive and logistically almost impossible (see Box 3). Even if all the conditions enumerated could be satisfied, it is probably now no longer opportune to conduct such a trial. Family-centred care is too well known, at least as a term and at least as a model whose parts have been implemented in some places, with other tenets in place in others, that it would be impossible to avoid a great deal of contamination. There is no “blank sheet” to be found on which an intervention could be implemented.

Discussion and Conclusion

So what we are doing about family-centred care? Several studies, completed and underway, are measuring health staff’s attitudes to working with children and working with their parents [25-28]. To date, all have found that staff score working with children significantly more positively than working with their parents. While this may relate to the fact that they choose to work with children, if family-centred care was being effectively implemented then there would theoretically be no difference. A qualitative study is examining the concept of who “owns” the child in hospital [29] and this may reveal whether such a subtle concept is affecting how parents and health professionals communicate. It is common to hear nurses and doctors talking about “my patient” and the power of language could mean that this sets up potential conflict. Other work is examining if socially vulnerable parents who seek healthcare for their children are disadvantaged [30] and that the healthcare of the children is therefore compromised. These studies will shed more light onto why family-centred care is so fraught and help find effective alternatives.

An alternative to family-centred care is emerging. Professor Bernie Carter in England, UK, writes of “child-centred care”, which she defines as a model where “children and their interests need to be at the centre of our thinking and our practice” [31]. Family-centred care sets parents at the centre of the child’s admission, while child-centred care sees children as active agents, with recognition of their right to participate in their care. Carter conceptualises it as the child “in family” *versus* “and family”. The child is a key and active member of the partnership with health professionals, who need to recognise that children’s views may not match their parents’ views, while still acknowledging the centrality of parents for the wellbeing of children. Child-centred care considers the whole child, not simply the illness or condition and is concerned with the overall experience of the child and family. It treats children and young people and parents as partners in care and integrates and co-ordinates services around the child’s and family’s

particular needs. Child-centred care helps the child graduate smoothly into adult services at the right time and works in partnership with children, young people and parents to plan and shape services and to develop the health workforce.

The concern with child-centred care, (or any alternative to family-centred care, for that matter) is that it, too, will become the same 'sacred cow' that family-centred care is now. To make it work, commitment by leaders of all health professions and managers of health services is needed. That requires education and lobbying and, importantly, discussions with policy makers such as ministers for health and social care and executive level directors. Essentially, though, it needs the commitment of those who will use it - the health professionals, health service staff and children, young people and parents for whom it is designed.

Conflicts of Interest

I declare no conflicts of interest.

References

- [1] Shields, L., Pratt, J., Davis, L.M. & Hunter, J. (2007). Family-centred care for children in hospital. *Cochrane Database of Systematic Reviews* Issue 1. Art. No.: CD004811.
- [2] Shields, L., Zhou, H., Pratt, J., Taylor, M., Hunter, J. & Pascoe, E. (2012). Family-centred care for hospitalised children aged 0-12 years. *Cochrane Database of Systematic Reviews* Issue 10. Art. No.: CD004811..
- [3] Trivette, C.M., Dunst, C.J., Allen, S. & Wall, L. (1993). Family-centeredness of the Children's Health Care Journal. *Children's Health Care* 22(4) 241-256.
- [4] Higgins, J.P.T. & Green, S. (eds.). (2011). *Cochrane Handbook for Systematic Reviews of Interventions* Version 5.1.0 [updated March 2011]. The Cochrane Collaboration. Available from www.cochrane-handbook.org.
- [5] Bolton, C.M. (2004). An evaluation of the quality of different forms of early postoperative care in children following tonsillectomy. Unpublished PhD thesis, University of Melbourne, Australia.
- [6] Shields, L., Zhou, H., Taylor, M., Hunter, J., Munns, A. & Watts, R. (2012). Family-centred care for hospitalised children aged 0-12 Years: A systematic review of quasi-experimental studies. *JBI Library of Systematic Reviews* JBL000423 10 (39) 2559-2592.
- [7] The Joanna Briggs Institute. (2011). *The Joanna Briggs Institute Reviewers Manual 2011 Edition*. Adelaide: The Joanna Briggs Institute.
- [8] King, S., Rosenbaum, P.L. & King, G. (1995). The measures of processes of care (MPOC): a means to assess family-centred behaviours of health care providers. Ontario, Canada: Neurodevelopmental Clinical Research Unit, McMaster University.
- [9] Watts, R., Zhou, H., Shields, L., Taylor, M., Munns, A. & Ngune, I. (2014). Family-centred care for hospitalised children aged 0-12 Years: A systematic review of qualitative studies. *JBI Library of Systematic Reviews* 12 (7) 204-283.
- [10] Burlingham, D. & Freud, A. (1942). *Young Children in War-Time*. London: Allen & Unwin.
- [11] Shields, L. & Mohay, H. (2001). John Bowlby and James Robertson: theorists, scientists and crusaders for improvements in the care of children in hospital. *Journal of Advanced Nursing* 35 (1) 50-58.
- [12] Spitz, R.A. (1945). Hospitalism: an inquiry into the genesis of psychiatric conditions in early childhood. *Psychoanalytic Study of the Child* 1,53-74.
- [13] Platt, H. (1959). *The welfare of children in hospital: report of the committee*. London: Ministry of Health.
- [14] Citizens' Committee on Children of New York City. (1955). *Liberal visiting policies for children in hospitals*. *Journal of Pediatrics* 46,710-716.
- [15] Institute for Patient-and-Family-Centered Care. (2015). *What is patient and family-centered care?* Available at: <http://www.ipfcc.org> (last accessed 10 January 2015)
- [16] Darbyshire, P. (1994). *Living with a sick child in hospital: the experiences of parents and nurses*. London: Chapman and Hall.
- [17] Shields, L., Pratt, J. & Hunter, J. (2006). Family-centred care: a review of qualitative studies. *Journal of Clinical Nursing* 15 (10)1317-1323.
- [18] Mikkelsen, G. & Frederiksen, K. (2011). Family-centred care of children in hospital - a concept analysis. *Journal of Advanced Nursing* 67 (5) 1152-1162.
- [19] Tse, Y (2013). Children thrive on companionship, not single rooms. *British Medical Journal (Clinical Research Edition)* 347, f6335.
- [20] Shields, L. & Tanner, A. (2004). Costs of meals and parking for parents of hospitalised children in Australia. *Paediatric Nursing* 16 (6)14-18.
- [21] Siffleet, J., Munns, A. & Shields, L. (2010). Costs of meals and parking for parents of hospitalised children in an Australian paediatric hospital. *Neonatal, Paediatric and Child Health Nursing* 13 (3) 7-11.
- [22] Shields, L. (2002). The Parent-Staff Interaction Model of Pediatric Care. *Journal of Pediatric Nursing* 17 (6) 442-449.
- [23] Shields, L. (2010). Questioning family-centred care. *Journal of Clinical Nursing* 19 (17-18)2629-2638.
- [24] Smith, J., Swallow, V. & Coyne, I. (2015). Involving parents in managing their child's long-term condition-a concept synthesis of family-centered care and partnership-in-care. *Journal of Pediatric Nursing* 30 (1) 143-159.
- [25] Aggarwal, S., Chadha, P., Kalia, S., Richardson, S., Winterbottom, L. & Shields, L (2009). Perceptions of family-centred care: a UK pilot study of the Shields and Tanner questionnaires. *Neonatal, Paediatric & Child Health Nursing* 12 (2) 25-29
- [26] Shields, L., Mamun, A., Pereira, S., O'Nions, P. & Chaney, G. (2011). Measuring family centred care: working with children and their parents in a tertiary hospital. *International Journal of Person Centered Medicine* 1 (1) 155-160.
- [27] Gill, F., Pascoe, E., Monterosso, L., Young, J., Burr, C., Tanner, A. & Shields, L. (2013). Parent and staff

perceptions of family-centred care in two Australian children's hospitals. *European Journal for Person-Centered Healthcare* 1 (2) 317-325.

[28] Shields, L., Mamun, A., Flood, K. & Combs, S. (2014). Measuring family-centred care: working with children and their parents in two second level hospitals in Australia. *European Journal for Person Centered Healthcare* 2 (2) 206-211.

[29] Shields, L., Kristensson-Hallström, I., Kristjánsdóttir, G. & Hunter, J. (2003). Who owns the child admitted to hospital: a preliminary discussion? *Journal of Advanced Nursing* 41 (3) 213-222.

[30] Zappia, T., Chapman, R., Blackwood, D., Watkins, R., Wardrop, J. & Shields, L. (2012). Lesbian, gay, transgender and bisexual parents seeking health care for their children: a systematic review of the literature. *World Views in Evidence Based Nursing* 9 (4) 200-209.

[31] Carter, B., Bray, L., Dickinson, A., Edwards, M. & Ford, K. (2014). *Child-centred nursing: promoting critical thinking*. Thousand Oaks, CA: SAGE Publications Ltd.