

Editorial: Family-centred care – points to ponder

Linda Shields *PhD, FRCNA*

Editor, Neonatal, Paediatric and Child Health Nursing

Conflict of interest: nil

Funding: nil

Ethical approval: N/A

Guarantor: LS

Contributorship: LS

Acknowledgements: nil

Family-centred care (FCC) (with its affiliated terms "parent participation", "partnership in care" and "parental involvement") is a concept much discussed and touted (at least within paediatric, and increasingly adult, healthcare services) across many countries, both developed and developing and across cultures – Western and non-Western. A policy of FCC will be found in most hospitals where children are nursed. Nonetheless, it is becoming apparent that FCC may not be working. Family-centred care is defined as "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 or person and in which all the family members are recognised as care recipients"¹. This definition is preliminary and needs further examination and debate; however, it encapsulates what FCC is about. According to the Institute for Family-Centered Care in the United States, FCC consists of a series of elements, including, amongst others, the importance of dignity and respect, the sharing of information, the need for collaboration between staff and parents, as well as participation of parents and effective communication². All this sounds great, but can it work, or is FCC really, as Darbyshire said in 1994³, "a wonderful ideal, but very difficult to implement in practice?"

At present, a group of us is updating a Cochrane Systematic Review about FCC⁴ and while we cannot pre-empt the findings of the update, one thing that is becoming obvious is that, as with the original review, there is scant research about whether or not FCC works, or if it makes any difference to children, families or the staff caring for them. A recent systematic review of parent participation⁵ also found that scant evidence about the efficacy of FCC exists; rather most is descriptive, lacks rigour and is inconclusive. If this is the case, then it must be time for us, as nurses who care for infants, children and young people, to ask if there is a better way to deliver healthcare.

What is needed is a large-scale randomised, controlled trial (RCT) of a whole service, system-wide FCC intervention. This would include physical and material facilities such as appropriate parent accommodation, as well as extensive education programmes for all staff, including ancillary and administration personnel; and education programmes

for children and their families, community services such as schools and welfare providers and policy makers and politicians who make decisions about healthcare delivery. A RCT such as this could be done by cluster randomisation with an individual hospital treated as a cluster and randomised to control or intervention group. It would require a large number of stand-alone children's hospitals run along similar lines, but geographically separate to minimise contamination across sites. I suggest that the only country in the world where such conditions exist is the United Kingdom, where there are over 30 free-standing, autonomous children's hospitals, which, because of the universality of the National Health Service, are all run similarly. Of course, such an experiment would be extremely costly and this is probably why such a project has not been attempted.

While we wait for a research body to fund a RCT, we do have an ever-increasing body of qualitative research around FCC, which generates a large degree of concern. While qualitative research cannot, by definition, tell us whether or not FCC works, it can suggest that something is very wrong with its current implementation. There is also a body of descriptive research which describes problems with FCC models, but similarly, because such studies lack the rigour of a RCT, they cannot tell us about cause and effect.

Darbyshire³ was possibly the first to suggest problems with FCC and recent studies increasingly suggest that problems continue. Coyne in 1995⁶, 1996⁷ and 2008⁸ consistently describes nurses using coercion to make parents fit the behaviour expected by the nurses, parents becoming resentful for being made to do what they see as nurses' work and nurses who expect parents to stay whether or not the parents feel they were able. Hughes⁹ in an Irish study, found discrepancies between nurses' and parents' attitudes to FCC, while a literature review from the UK¹⁰ found themes about lack of communication between parents and nurses and limited negotiation about parental involvement. Another UK study¹¹ found that parents were given little choice about their roles when caring for their technology-dependent children; a Canadian study¹² of parents and a range of health professionals found that collaboration with parents was not fully understood or implemented by either parents or health professionals. Studies from the United States¹³,¹⁴ demonstrate discrepancies about communication and expectations of care. Australian studies¹⁵,¹⁶, also, have found serious misunderstandings about FCC between staff and parents, often influenced by a breakdown in communication. Research from the Nordic countries¹⁷,¹⁸ has found similar problems to all of these, despite having one of the best healthcare systems in the world, strongly supported by

welfare systems that see parents given paid time off work to care for sick children¹⁹. Nor are these problems restricted to paediatrics. Neonatal²⁰⁻²² and adolescent care^{23, 24} are suffering as well.

Problems with FCC are not restricted to Western countries. A study from Tanzania²⁵ described a lack of parent-friendly wards and untrained staff who do not understand FCC, while a Thai study²⁶ demonstrated that parents had no choice in their level of involvement. Parents in an Iranian study²⁷ stated that they had not been supported during their child's admission, while another²⁸ found a lack of communication and understanding of negotiation by both parents and staff caused problems with the implementation of FCC.

So where does this leave us, as nurses who are supposed to be implementing FCC, often as dictated by policy and our superiors? Surely we must stand back, ask if FCC is achievable, or is Darbyshire right in saying it may be unobtainable in practice? Should we wait until a RCT is done before we begin to question what we are doing with children and families? While the emphasis on existing research is largely on parents (and sometimes children), where do the health professionals sit in this? Often we are thought to be the "baddies", because we hold the power in the relationship with parents and, therefore, should be able to craft our interactions with them so that FCC works. But can we do that? Little research examines what it means for health professionals when they have to "partner" or negotiate with parents and we must acknowledge that some parents can be difficult²⁹. Hospitals put pressure on staff to implement FCC, but are the parents educated as to what FCC is really about and do they hold appropriate expectations of the hospital's ability to provide it? Are managers and executives knowledgeable about FCC, or do they just see parents as caregivers and decrease nursing staff numbers accordingly?

My next question is: is it ethical to continue to push FCC as a way of delivering care when, patently, there are so many problems with it and these problems seem to be universal? Surely the time has come for us all to do one of two things: either to make sure all conditions are in place to make FCC work (effective, appropriate and long-term education of all, including parents, children, the community, policy makers, politicians, the media – the list is long), or to look around for something to replace FCC.

At this stage, I have few suggestions, but I enjoin all readers of *Neonatal, Paediatric and Child Health Nursing* to begin thinking about this and ultimately lead the world in producing an alternative way of caring for families.

References

- Shields L, Pratt J, Hunter J. Family-centred care: a review of qualitative studies. *J Clin Nurs*. 2006; 15(10):1317-23.
- Institute for Family-Centered Care. Family-centered care: Frequently asked questions [Internet]. Maryland USA: Institute for Family-Centered Care; 2005 [cited 13 June 2008]. Available from: <http://www.familycenteredcare.org/about/index.html>
- Darbyshire P. *Living with a Sick Child in Hospital: the Experiences of Parents and Nurses*. London: Chapman & Hall; 1994.
- Shields L, Pratt J, Davis L, Hunter J. Family-centred care for children in hospital. *Cochrane Database Syst Rev*. 2007; Issue 1. Art. No.: CD004811. DOI: 10.1002/14651858.CD004811.pub2.
- Power N, Franck L. Parent participation in the care of hospitalised children: A systematic review. *J Adv Nurs*. 2008; 62(6):622-641.
- Coyne IT. Partnership in care: parents' views of participation in their hospitalized child's care. *J Clin Nurs*. 1995; 4(2):71-9.
- Coyne IT. Parent participation: a concept analysis. *J Adv Nurs*. 1996; 23(4):733-40.
- Coyne I. Disruption of parent participation: nurses' strategies to manage parents on children's wards. *J Clin Nurs*. 2008; 17(23):3150-8.
- Hughes M. Parents' and nurses' attitudes to family-centred care: an Irish perspective. *J Clin Nurs*. 2008; 18:304-11.
- Corlett J, Twycross A. Negotiation of parental roles within family-centred care: a review of the research. *J Clin Nurs*. 2006; 15(10):1308-16.
- Reeves ES, Timmons S, Dampier S. Parents' experiences of negotiating care for their technology-dependent child. *J Child Health Care*. 2006; 10:228-39.
- MacKean GL, Thurston WE, Scott CM. Bridging the divide between families and health professionals' perspectives on family-centred care. *Health Expect*. 2005; 8:74-85.
- Galvin E, Boyers L, Schwartz PK, Jones MW. Challenging the precepts of family-centred care: testing a philosophy. *Pediatr Nurs*. 2000; 26(6):625-32.
- Neal A, Frost M, Kuhn J, Green A, Gance-Cleveland B, Kersten R. Family-centered care within an infant-toddler unit. *Pediatr Nurs*. 2007; 33(6):481-5.
- O'Haire S, Blackford JC. Nurses' moral agency in negotiating parental participation in care. *International J Nurs Res*. 2005; 11:250-6.
- Roden J. The involvement of parents and nurses in the care of acutely-ill children in a non-specialist paediatric setting. *J Child Health Care*. 2005; 9(3):222-40.
- Kristensson-Hallström I, Elander G. Parents' experience of hospitalization: different strategies for feeling secure. *Pediatr Nurs*. 1997; 23(4):361-76.
- Kristensson-Hallström I, Elander G. Decision-making during hospitalization: parents' and children's involvement. *J Clin Nurs*. 2004; 13:367-75.
- Shields L, Kristensson-Hallström I, Andershed B, Jackson K, Eriksson M. Nursing and health care in Sweden. *Aust J Adv Nurs*. 2002; 20(1):20-6.
- Fegran L, Fagermoen MS, Helseth S. Development of parent-nurse relationships in neonatal intensive care units – from closeness to detachment. *J Adv Nurs*. 2008; 64(4):363-71.
- Higman W, & Shaw K. Nurses' understanding about the delivery of family-centered care in the neonatal unit. *J Neonatal Nurs*. 2008; 14(6):193-8.
- Fegran L, Helseth S. The parent-nurse relationship in the neonatal intensive care unit context – closeness and emotional involvement. *Scand J Caring Sci*. 2009; 23(4): 667-73.
- Gross V, Goldin J. Dynamics and dilemmas in working with families in Inpatient CAMH services. *Clin Child Psychol Psychiatry*. 2008; 13(3):449-61.
- Soldano C, Markell G. Parent involvement in health concerns for youth: the issue of adolescent immunization. *J Sch Health*. 1997; 67(7):292-93.
- Manongi RN, Nasuwa FR, Mwangi R, Reyburn H, Poulsen A, Chandler C. Conflicting priorities: evaluation of an intervention to improve nurse-parent relationships on a Tanzanian paediatric ward. *Hum Resour Health*. 2009; 7:50-60.
- Pongjaturawit Y, Chontawan R, Yenbut J, Sripichayan K, Harrigan RC. Parent participation in the care of hospitalized young children. *Thai J Nurs Res*. 2006; 10(1):18-28.
- Sarajarvi A, Haapamaki ML, Paavilainen E. Emotional and informational support for families during their child's illness. *Int Nurs Rev*. 2006; 53(3):205-10.
- Aein F, Alhani F, Eesa M, Anoshirvan K. Parental participation and mismanagement: a qualitative study of child care in Iran. *Nurs Health Sci*. 2009; 11(3):221-7.
- Stein MT, Jelinek' MS, Wells RD. The difficult parent: a reflective pediatrician's response. *Pediatrics*. 2004; 114(5):1492-5.