Family-centred care: The role of consumer organisations and the need for further research

If one goes to a children’s hospital anywhere in the world, one will find a policy about family-centred care. It may be a formal written policy, or it may be informal with nurses and other health professionals happy to say that they implement family-centred care. Family-centred care means that when a child comes into a health service for care, that care is planned around the whole family and not just the individual sick child. As one who has done two major theses on family centred care, as well as Cochrane and Joanna Briggs Institute reviews of the existing evidence, I can say that the implementation of family-centred care is at best problematic, and at worst harmful because, often, it is not well understood and therefore not done appropriately.

Family-centred care as a model from which to deliver care to patients has been around for a long time. It grew out of the movement that brought about improvements in the way children were cared for in hospital, most notably allowing and encouraging parents to stay with a hospitalised child. This began in the United Kingdom (UK) with the publication of the Platt Report in 1959, and a very active parents’ lobbying movement. Lobby groups grew up around the world, with the UK, Europe (including the Nordic countries), Canada and Australia taking the lead (see Figure 1). These groups recognised that essential and core to family-centred care is the idea of the centrality of the family (however defined by that family) in a child’s life and the need to ensure that during a potentially emotionally traumatic activity such as admission to hospital, the family is the unit for whom care is planned.

While aligned with person-centred care, family-centred care can be slightly different, given its emphasis on the family. Bernie Carter’s new model of child-centred care is perhaps more closely related to person-centred care. David Edvardsson has described person-centred care as the integration of the relational aspects of life with the biological and the recognition of the need to integrate the ‘being with’ with the ‘doing for’ in nursing. It is the same for family-centred care, with the whole family as the unit with which one implements the ‘being with’ and ‘doing for’. Kim Lützen suggests that there is a moral imperative to implement person-centred care, and so for family-centred care. However, wonderful as it sounds, we must hark back to Philip Darbyshire’s work in the early 1990s when he described family-centred care as an ideal way to provide care for hospitalised children that is very difficult to implement effectively.

There have been some attempts to measure family-centred care in health services. Medical researchers have used the Measures of Processes of Care (MPOC) questionnaire in a wide range of medical specialties. Designed to measure the way care is delivered in disability services, I argue that the MPOC does not measure family-centred care, rather, it measures what its name implies—the processes involved in care delivery. A useful tool indeed, but not necessarily one that gets to the core of family-centred care.

In an attempt to measure at least one component of family-centred care, I devised a brief questionnaire that assesses the way health professionals view working with children and their parents. The theory behind the questions is that if one is implementing family-centred care effectively, then one would feel as positive about working with parents as with working with children. This questionnaire is being used in a wide range of countries, in various care settings. It invariably demonstrates that health professionals who work with children and families score working with children more positively than working with parents, and the differences in the scores are inevitably statistically significant.

If this is the case, maybe such attitudes are at the core of why family-centred care is so difficult to implement effectively.

As I have described recently, there is sparse research in the form of testable evidence about family-centred care and so we cannot say whether it works or not, nor whether it makes any difference to children and families (or health services). However, a growing body of qualitative evidence indicates serious problems with the way family-centred care is delivered in health services. In other words, the model is a very good one, but we do not know if it works, and we do not know that while health services and health professionals of every ilk espouse it as a model of care, in many instances it is so poorly implemented that it could cause harm. It is time to seek another way.

Bernie Carter has provided a new model of ‘child-centred care’, and suggests that family-centred care, worthy as it sounds, takes the focus of care away from the one who should be at its centre: the child. Indeed, children’s voices and opinions are often overlooked in this big adult world of health care. Various researchers in nursing attempt to ensure that children’s voices are heard, for example, Imelda Coyne in Ireland, Inger Hallström in Sweden, Veronica Swallow, Bernie Carter, Duncan Randall, and Jane Coad in the UK, and Mandie Foster in New Zealand. These are important works and could bring the best perspective to the implementation of family- and child-centred care, and might help to explain what is needed for effective health care delivery to children.
This brings me to the main point of this editorial. Kim Lützen’s comments about person-centred care emphasise the imperative that a person’s needs and rights to be involved, either actively or passively, in their own health care decisions must be respected. Children, too, need such involvement. To do this, they need education about what such involvement involves, and they need the skills and knowledge to inform decisions. Many of the lobby organisations shown in Figure 1 have suffered a decline in interest (and funding) over the last two decades, probably because care for children in health services has improved dramatically since the groups came into being in the 1960s and 1970s. Nonetheless, it is important to recognise that health care, also, has changed drastically since then, with short stay admissions, new technologies, hospital in the home and so forth. Do health care recipients, in this case, children and parents, know their rights and responsibilities in this modern world of health care? Can they be equal partners in their own health decisions? Do they understand the issues involved? While researchers like Swallow, Carter, Hallström, Randall, Foster and Coad work to discover what children really need and what education needs to be given them and their parents to ensure their informed involvement, there is a very real role for the lobby groups. While I am reluctant to use the word ‘consumer’ I can think of no other, at least in English, that is useful in this context. Hence, I must talk of these as consumer organisations, run by parents and children, and which are the vehicles for community education.

Most of these organisations run on minimal funding, often annual grants from government, and this makes their existence tenuous. Sponsorship is needed but requires careful consideration as it can be an ethical nightmare, for example, no such organisation would consider accepting funding from, say, a tobacco company. In this world of ever-tightening resources, ethical sponsorship is hard to find. However, the organisations are vital to the protection of high standards of care of children and families in health services, and cannot be allowed to disappear. An examination of their websites shows their educational abilities. If their reach was wider (in other words, if they had the funding to employ a raft of appropriate people with the required skills) then they could do much more. As a board member of the Australian Association for the Wellbeing of Children in Healthcare (AWCH), I can give examples of what could be done. AWCH is one of the groups that is funded by annual government grants, but provides a wide range of services to the children and families of Australia. For example, they have many education resources which are assiduously kept up to date, they have education packages about hospital admission which are free to all, and some education for which they have to charge small amounts. If they could secure more funding, they could run programmes in schools, undertake hospital evaluations, provide counselling related to health care usage for children and parents; the list of potential activities is endless. I am sure the same occurs for all the other similar lobby groups around the world.

So to summarise, family-centred care is a wonderful ideal but difficult to implement effectively and is not grounded in rigorous evidence. Child-centred care may provide an alternative model for care delivery. In essence, though, the important thing is to educate not just health professionals about the needs of children and families during a health service interaction, but the children and parents themselves. Existing consumer organisations are the ideal vehicles to provide such education. Their mission, to enhance the care of children in health services, is well supported by the knowledge and experience of their staff and members, but they need community and government recognition, with appropriate ongoing funding, and support from health care institutions, health professionals, and the children and parents who they serve.

References


Linda Shields

*Professor of Nursing, School of Nursing, Midwifery and Indigenous Health, Charles Sturt University, Bathurst, NSW, Australia; Honorary Professor, School of Medicine, The University of Queensland, Brisbane, Queensland, Australia*