Family-Centred¹ Care: Effective Care Delivery or Sacred Cow?

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Abstract

Family-centred care as a way to care for children in hospitals has become ubiquitous in the world of paediatrics. It evolved from work of pioneers in theories of maternal and child attachment, and paralleled the evolution of paediatric nursing as an academic (and evidence-generating) discipline. However, in the last decade, doubts have been sewn as to its efficacy and workability, due to the lack of rigorous evidence about whether or not it works, or as to whether or not it makes a difference to the children and families for whom it is purported to care.

This paper examines the historical evolution of family-centred care, discusses the current research about it, and poses questions around the ethics of continuing to use a model around which so many questions are generated.

Introduction

A visit to most paediatric health services almost anywhere in the world will find the term "family-centred care" in a variety of languages, on policy documents, frameworks, models of care, guidelines and people's lips (Shields, 2010a). The Institute for Patient- and Family-Centered Care in America (2011) provides a list of elements of family-centred care, but most definitions are descriptive. Scholars suggest that family-centred care is a wonderful ideal but very difficult to implement in practice (Darbyshire, 1994), while some qualitative studies (Coyne and Crowley, 2007; Coyne, 2008) reflect an inability of health service staff to effectively implement a family-centred care model.

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" (Shields, et al. 2006, p. 1318). In countries around the world we have become used to seeing parents as an integral part of the child's care. In all countries, it is common to see parents helping to care for their child in a health care encounter. This is as true in developing countries as it is in wealthy developed nations (Shields, 1999; Shields and Nixon, 1998). This paper examines family-centred care, its evolution and development, and describes research about it. Questions are posed as to its applicability and the ethics of continuing with an untested model.

An historical overview

The evolution of family centred care started with the first freestanding children's hospitals. In 1802, the first children's hospital was opened in Paris, quickly followed by Vienna and St.

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¹ The British spelling, centred, is used in this paper.

Petersburg (Hayes, 1965). The first paediatric hospital in an English-speaking country was opened in 1856, the now famous Hospital for Sick Children, Great Ormond Street, London. As children's hospitals evolved, and nursing developed as a profession, styles of paediatric nursing developed. Until the 1960s, children's wards were regimented and controlled; tidiness and discipline took precedence over the emotional needs of the child (Shields and Nixon, 1998; Jolley and Shields, 2010). Children were often tied in their beds, ward furniture was adult size, and prevention of cross infection was paramount (Watkins and Lewis-Faning, 1949). Importantly, parents were very often excluded from the hospital ward in which the child was admitted. Nurses and doctors of the day genuinely believed that the presence of parents caused the child severe emotional upset, and reasoned that it was best if parents did not visit at all (Alsop-Shields and Mohay, 2001). Consequently, children who were admitted to hospital with long-term diseases such as tuberculosis or juvenile rheumatoid arthritis may not have seen their parents for up to three years, a common length of an admission for such conditions. Admission to hospital for a small child was a traumatic and distressing event, and was equally so for parents.

Some enlightened researchers and clinicians began to question such practices and attitudes in the 1920s and 30s (Jolley and Shields, 2009). Sir James Spence, a paediatrician in Newcastle-upon-Tyne in England admitted breastfeeding mothers with their infants (Spence, 1960), while in the United States, Renée Spitz, a child psychiatrist, coined the term "hospitalism" to describe a child who was highly institutionalized from long-term admission to hospital (Spitz, 1945). Two British men were arguably the most important influences on changes in attitudes about the hospitalization of children. John Bowlby, a child psychiatrist working in the Tavistock Clinic in London in the 1940s and onwards became the preeminent theorist about maternal and child attachment (Alsop-Shields and Mohay, 2001). He demonstrated that a child separated from his or her mother at an early age and for an extended period of time often suffered psychopathology in later childhood and adolescence (Bowlby, 1940; 1953). James Robertson, a social worker from Scotland, worked with Bowlby on maternal and child attachment. After his own small daughter had been admitted to hospital, Robertson and his wife, Joyce, were distressed by the changes in their daughter's behaviour after the hospital admission (Robertson, 1962). James decided to dedicate his work about attachment theory to the effects of hospital admission on small children. The Robertsons, in conjunction with Bowlby, made a series of films which show the emotional effects of hospital admission on children (Robertson, 1953; 1958; 1967; Robertson and Robertson, 1968; 1969; 1971; 1973), and they became the missionaries, taking the films around the world (Alsop-Shields and Mohay, 2001). As a result of the work of Robertson and Bowlby, the British government implemented a select committee of parliament to examine the welfare of children in hospital. It was chaired by Sir Harry Platt, at the time the chairman of the Royal College of Surgeons, and its resultant report came to be known as the Platt Report (1959), which is still referred to today as the cornerstone of changes in paediatric hospital practice (Priddis and Shields, 2011). The Platt Report (1959) contained 55 recommendations, however the most important were that the mother be admitted with the child, that accommodation be provided for the mother, and that school and play facilities be provided for children.

Around this time, changes were emerging in nursing, and these had a profound effect on the way care was delivered. The move of nursing into the university sector began in the United States at the beginning of the 20th Century (Donohue, 1996), with most other countries slow to follow (for example, the transition was complete in 1993 in Australia, while it was not until 2000 that it occurred in the United Kingdom, and in many countries, has still not happened). However, the macadamisation of nursing education meant an increasing interest in the generation of nursing specific knowledge, and consequent research. Out of this, models of nursing care of children developed as a field of study. One of the first to emerge was "care-by-parent" (Goodband and Jennings, 1992), which saw purpose built units in paediatric facilities designed to be as homelike as possible. In these, children were admitted with as many of their family members as they required, so that care could be given with as little compromise of normal home life as possible. Despite studies which showed that in the long run, such units were cost effective (Evans and Robinson, 1983), most children's hospitals could not budget for them, and few were built. In the UK, "partnership-in-care" was devised by Anne Casey in 1988 (Casey, 1988; 1995). In this model, parents work in partnership with nurses to provide care for their child, in fact, the parent gives the so called "basic" care² while the nurse educates and supports the parent to do so. Partnership-in-care, while commonly cited, was not without its problems. In 1995, Coyne examined parents' perceptions of partnership-in-care. Parents viewed their participation as necessary for the child's well-being, a non-negotiable part of parenthood. Nurses were seen as too busy to provide consistent care. Parents were prepared to learn more complex care, but only when necessary, preferring to leave it to the nurses because of the anxiety it caused. Information, communication and negotiation were the most important part of ensuring successful partnerships with the nurses.

From these models, family-centred care evolved, and by the 1970s was to be found in many children's hospitals' policy and mission statements. Family-centred care is based on several elements. These elements of family-centred care, as defined by the Institute for Patient and Family-Centered Care (2011) are:

- 1. Recognizing that the family is the constant in a child's life, whereas service systems and personnel within those systems fluctuate
- 2. Facilitating parent/professional collaboration at all levels of health care
- 3. Recognizing family strengths and individuality, and respecting different methods of coping
- 4. Sharing unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner
- 5. Encouraging and facilitating parent-to-parent support
- 6. Understanding and incorporating the developmental needs of infants, children, adolescents, and their families into health care systems
- 7. Implementing appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families

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² The concept of "basic" care is contentious, as all care given to a patient/client by nurses is complex. Even when assisting patients onto bedpans (surely one of the most "basic" functions or a nurse's role), the nurse is assessing the patient for a range of indicators that may demonstrate changes in condition etcetera.

8. Assuring that the design of the health care delivery system is flexible, accessible, and responsive to family needs

While these elements all sound (and are) important, some investigators began to question the way family-centred care was being delivered. Darbyshire (1994; 1995) suggested that the complexities of family-centred care were minimized in the literature. While a wonderful ideal, it is, in reality, extremely difficult to implement because of the judgemental attitudes of nurses towards parents, resulting in the feeling that they are "parenting in public", while nurses feel they are "nursing in public". He suggested that for family-centred care to succeed, understanding and empathic communication between parents and nurses was required.

What is "family-centred care"?

So what is this thing we call "family-centred care"? We understand the premises on which it is based, but in practical terms, what is required? Firstly, and as a basic and vital construct, we must recognize the family as the centre point in child's life. Structure and environment of a children's health facility needs to facilitate family-centred care, with parents' accommodation, bathrooms, kitchens, meals, laundry, parking, and other structural needs provided. Parental presence for interventions (as wanted by the family) is an important part of the model, and cultural factors of all colours are hugely influential and must be taken into consideration. Education of staff and the family is fundamental, as is effective communication between parents, children and all staff. Support for parents, siblings, extended family is needed, and the involvement of consumer groups will enhance the way care is delivered, and expectations (held by parents and children) of that care.

There exist, however, some misperceptions about family-centred care. One commonly heard is the statement that hospitals in developing countries implement family-centred care much better than those in developed nations, because the family is always allowed and encouraged to stay with hospitalized children (and adults) (Shields, 2010a). However, this can be a fallacious argument, as in poor nations with restricted health spending, family members have to stay as there may be few nurses to give care. Other misunderstandings about family-centred care are that parents are impelled and expected to give "basic care", with an accompanying expectation that parents will stay in the hospital with their admitted child. Some managers in hospitals see parents in a ward as replacement for nursing staff, which, of course, they are not, and managers need to be made aware that if family-centred care is being implemented effectively, the unit of care is often a group of people (the family) rather than just a single individual patient, and so more nursing staff are needed, not fewer.

Within many health facilities, parents are encouraged to be with their child for single interventions, for example venipuncture, or anaesthesia induction. While this is important, unless all parts of the service implements all facets of family-centred care, the presence of the parents for a single intervention does not constitute a family-centred care model. In addition, staff cannot expect that parents will want, or be able, to be present. Parents may have other pressures in their lives, other children for whom they care, or may be too overwhelmed and frightened about what is happening to their child to be able to be present. Finally, it must always be remembered that parents are not there to meet needs of health professionals, indeed, the converse is true, and parents must always be given the consideration and respect that is an inherent part of any health care interaction.

Current research

Anyone investigating concepts such as family-centred care have to grapple with definitions that were not problematic before the world recognized and accepted the diversity of populations and cultures. For our purposes, we define "family", and "parent" as whatever the particular family perceives these to be. In other words, if a family says that its unit comprises extended family, then when investigating family-centred care, that is the family we recognize. Similarly, a parent is the primary caregiver for the child/re, and whoever is identified as such by the child and family. The research described from here on is founded on these broad definitions.

A Cochrane systematic review of the literature about family-centred care (Shields et al, 2007), and its update (soon to be published) has shown that there is no rigorous, reliable evidence that family-centred care works, or makes a difference. A growing body of qualitative research (Lam, Chang and Morrissey, 2006; Pyke-Grimm et al. 2006), though, describes grave concerns about how it is implemented. While qualitative research cannot prove or disprove anything, it provides profound insights into the topics under investigation. Importantly, in relation to family-centred care, similar themes are being described in studies across many countries. Some have found staff to be judgemental towards parents (Manongi, et al 2009); others that parents are being "punished" when they do not meet the expectations of health professionals caring for their children (Aien, et al. 2009). Sometimes, staff act as "gatekeepers" to the children, inhibiting parents' access if they are perceived as being unworthy (Roden, 2005). This leads to parents having to use strategies to have their needs met (Kristensson-Hallström and Elander, 1997), and in some cases parents are resentful at being made to do nurses' work (MacKean, 2005). At the root of this is major communication breakdown, and as effective communication is the lynch pin of successful family-centred care, it is not surprising that it seems not to be working.

Hospital admission of a child holds an inherent a degree of emotional trauma for any family. Over the last 10 years, research has shown that parents have certain needs when they have an ill child who is admitted to hospital (Kristjánsdóttir, 1995). In several studies in three different countries, parents indicated that they needed to feel they could trust the health staff caring for their child, that they, themselves, were trusted by the staff; and that all communication between parents, children and staff was effective. These needs were more important for parents than having physical needs, such as food and shelter, met. In these studies, staff—nurses, doctors and allied health professionals, were given matching questionnaires, and results showed that staff were more likely than parents to think that parents needed help to have these needs met (Shields, Hallström and O'Callaghan, 2003; Shields and Kristensson-Hallström, 2004; Shields, Hunter and Hall, 2004; Shields, Young and McCann, 2008). We can infer from that that either parents are more independent than staff think they are, or that staff are overly paternalistic. Other research in this area, using a scoring system to measure how health professionals score working with children and working with their parents, shows that while working with both groups is positive, working with children earns a more positive score than working with their parents (Shields, 1999; Aggarwal et al. 2009a; 2009b). While this may not be surprising given that health professionals who choose to work in paediatric health facilities, in the main, like children, it shows that family-centred care is not being effectively implemented—if it was there would be no difference between the scores for working with children and those for working with parents.

Some have tried to measure family-centred care. The Canadian "Measuring Processes of Care" (MPOC) questionnaire (King et. al 1995) was originally developed to use with families of children with disabilities. While valuable in its own right, the MPOC measures the way care is delivered. The level of environmental, structural and procedural process for family-centred care are measured by the raft of very good questionnaires available from the Institute for Patient- and Family-Centered Care in America (2011), However, these tools do not measure actual perceptions about family-centred care held by parents and staff. A set of questionnaires to measure perceptions of family-centred care held by parents and health professionals (Shields and Tanner, 2004) have 20 questions based around three concepts which constitute family-centred care: respect, collaboration, and support. These tools were developed from existing literature and qualitative interviews with parents and staff. They have been used in Australia and England in paediatrics, (Aggarwal et al. 2009) and used in an adult setting (Mitchell et al. 2009). At present they are being used in two paediatric hospitals in Australia (Gill et al. 2010). Ongoing statistical development will see further iterations of the questionnaire set. Preliminary results of a current comparative study shows differences between responses from 236 parents and 466 staff (nurses, doctors and allied health professionals) from two demographically similar tertiary paediatric hospitals. Scores of the three components of family-centred care, plus an overall score were compared between parents and staff, and parents demonstrated a significantly more positive attitude towards family-centred care than staff. This may indicate that staff need more education about family-centred care, and consequently may not be meeting families' needs.

There is a possible philosophical foundation to the interactions of parents and staff. Who "owns" the hospitalized child is a contentious issue (Shields, et al. 2003), and disagreement about this occurs, where the parents feel they own the child, while at the same time staff, by dint of the responsibility they feel for the child while in his or her care, think the child patient is "theirs". Consequently, conflict, or at least, compromised communication, can arise. Research into this interesting aspect of family-centred care is ongoing.

Of course, recognition must be made that not all parents and families are amenable to the best of intentions of health professionals caring for children in hospitals. It would be disingenuous to suggest that difficult parents do not exist. One such example is families where child abuse has occurred. Family-centred care is as important (if not more so) for these families as it is for others, as the essence of family-centred care is tailoring the care to meet the needs of the family (Shields, 2002), and these families have particular needs, for example, psychiatric and social work help, and only by meeting their specific needs can family-centred care work for "problem" families.

Is there an alternative?

In this paper, I have outlined what family-centred care is, how it works, and problems associated with its implementation. I argue that family-centred care remains the ideal model of care when a child is admitted to a health service, because the family remains the centre of a child's life. Indeed, common sense tells us that children need their parents during hospital

admission; however, we know that family-centred care is not working effectively. It is time to seek for alternatives.

One such could be cultural safety. In New Zealand, cultural safety has become the pillar of all interactions across government and social departments. It can work if we regard each family as a "culture". Cultural safety was first defined by a nurse, Irihapeti Ramsden, in 2002. It is the effective health professional practice of a person or family from another culture, as determined by that person or family (Ramsden, 2002). Three principles underpin cultural safety: recognition of diversity amongst and within cultural groups; an understanding of one's own culture and groups within that culture; and recognition of one's own, and others', unique cultural identity. These can all be applied to families. For effective implementation, cultural safety proscribes three steps for the health professional: 1. cultural awareness - one understands that difference exists; 2. one upholds cultural sensitivity by appreciating the legitimacy of difference, and by exploring power relationships with those seeking health care, and the impact these have; and 3. the resulting delivery of safe service/care defined by the recipients (Ramsden 2002).

Cultural safety is different to other models surrounding culture. Nurses, in particular, have become familiar with the term "transcultural" (Leininger, 1977), and "cultural competence" (Purnell, et al. 2011). In interactions guided by these models, power rests in hands of the health professional, while with cultural safety, power rests with the recipient. In short, and for our purposes, to give effective care to families, one must recognise that differences (between staff and families and between families) exist, celebrate those differences, be sensitive to possible misunderstandings which could arise, and use the philosophy of cultural safety to move the balance in power relationships within a health care encounter to the recipients.

A word of caution about any of these models needs to be noted. As with so many of the models found in health care, which sound good and read well on paper, cultural safety could become a "sacred cow" in the same way that family-centred care has (Shields, 2010a; 2010b). The fact that family-centred care can be found in many health services' policy documents, but without effective implementation in practice, means that it suffers from Humpty Dumpty's injunction in Alice in Wonderland: Through the Looking Glass: When I use a word, it means just what I choose it to mean—neither more nor less" (Carroll, 1872). It would serve no purpose to implement another model, for example cultural safety, to see it become as misused as family-centred care.

Conclusion

We have examined the evolution of family-centred care from early awareness of the need for parents to accompany a child during hospital admission, through to its ubiquity in modern paediatrics. Explanation of what a family-centred care model of care comprises and how it could be successfully implement has been described, along with injunctions about what it is not. Importantly, I have highlighted the lack of rigorous evidence about its effectiveness, and explained the growing body of qualitative research which consistently discovers problems in the application of the family-centred care model. An alternative model, cultural safety, may be the way forward if one regards each family as a separate "culture". However, caution should be used when implementing yet another model which may suffer the same fate as

others—that of looking good on paper and in policy, but unworkable and redundant in practice—in other words, becomes yet another "sacred cow".

The endpoint of this argument is the hospitalised child and his or her family. While I have no tested alternative for family-centred care, and believe that any model for paediatric health care needs to keep the family as the centre of the child's life, we must recognize that all our deliberations result in care for children and families. I suggest that it is unethical for health professionals, institutions and services to continue to promote a model which is untested and probably ineffective. We must search for a workable alternative. Only by doing so will we truly serve the children and families for whom we care.

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