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THE EVOLUTION OF FAMILY CENTERED CARE

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ABSTRACT

Aim: to explore the history of family-centered care.

Background: FCC developed after WW2, when nursing, then deeply paternalistic, had become asynchronous with changing social expectations for the care of hospitalized children.

Methods: historical review of literature reflecting development of pediatric models of care, using publications of classic theorists and others.

Results: development of FCC resulted from work US and UK researchers, theorists and advocates. Their research was right for its time and its acceptance was the result of social readiness for change resulting from people's experience of WW2.

Conclusion: WW2 brought about changes enabling emergence of lobby groups concerned with children in hospital, awakening of pediatric health professionals to family oriented practice, and development of models of care that allowed wide-scale adoption of FCC.

Introduction

Today, it is accepted that parents have a right to stay in hospital with their sick children, and it is understood that children need their parents especially when the children are ill. The development of this understanding has not taken place in a uniform fashion across the globe (Just, 2005), nor has the understanding of the social and psychological needs of the sick child developed through the employment of evidence-based practice and research. In this paper we put these developments into perspective and show the forces that were at work to cause nursing to take due account of the sick child's need for their parents. We argue that what is often now referred to as "family centered care" (FCC) has its roots in the most unlikely of places; not as might be assumed, in research, but in war-torn Europe of 70 years ago. Conventional accounts of this history (Just, 2005) often fail to account for the important effect of social change created by World War Two.

What is "family-centered care"?

"Family-centered 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). The Institute of Family Centered Care (2006) in the United States (US) has listed elements of which it consists (see Figure 1). Other terms connote similar things, for example, the term "parental participation", which means that accompanying parents are involved in undertaking aspects of the care of their hospitalized child (Darbyshire, 1995); "care-by-parent" where parents are housed with the sick child in a specially built unit which resembles the home (Goodband & Jennings, 1992); and "partnership-in-care", in which parents and nurses

work together to provide care for the sick child (Casey, 1995). These models of care were precursors to the formalised model known as FCC and all have come to contribute to this (unsubstantiated (Shields *et. al*, 2007)) cornerstone of current pediatric practice. To understand FCC fully, we must examine its development and history.

FIGURE 1 about here

A brief history of hospitalisation for children

In the middle years of the twentieth century, children were admitted to hospital without their parents, and parents were either not allowed to visit or could visit for perhaps only half-an-hour a week. In young children, this resulted in psychological trauma which was often serious and enduring in nature (Robertson, 1970). In this era, children were hospitalized for long periods of time, especially for chronic illnesses such as tuberculosis, which could result in a hospital stay of two years or more (Prugh *et. al*, 1953). In many such cases, the children did not see their parents during the whole admission (Robertson, 1970).

In a doctoral study, Jolley (2004; 2007) examined the history of children's nursing in the United Kingdom (UK) between 1920 and 1970 using oral history data obtained from those who were sick children at the time, and from those who cared for them. Participants were recruited from the elderly population in the UK between 2000 and 2003. Open, structured interview data were recorded, transcribed, validated and then analysed using a thematic approach. Jolley's study provides graphic evidence of the effects of separation from parents during a hospital admission, the trauma of which

was remembered decades later: here a gentleman in his seventies recalls an admission when he was four years old:

'When the matron did her rounds, you know she would come down the centre of the ward ... with her entourage and cape flowing and everybody was in fear and I really mean fear [emphasis] the nurses as well. I can see the old battle-axe now, coming down and criticising this, that and another ... I can remember being in fear of the matron, I was in fear of everything really. You were nearly in fear of [pause] moving off your bed or moving in bed really because everything had to be kept ... like that board [pointing], so straight. You know, I can't remember much laughing ... I don't know why I'm like this [cries] [pause]...' (Jolley, 2004, p. 125)

Here, a nurse looks back on the time when she was a student:

'And so this toddler that by now was distraught, sobbing, I went to pick him up. because he was just, he was just left on the cot to break his heart and sob, so I went to pick him up and just as I did, he was like a little monkey, his arms around me, and [laugh] I can still see him today, his little fingers ... I'm going to get upset again [crying] hanging up to me. [crying] [pause] [pause] it was awful [crying] [pause]. And so [crying] the good children's nurse came and put a harness on him and fastened him down [emphasis] [pause] and sob, sob, sob [meaning the child] it was awful. I think, one of the worst things and he was just left to get on with it [pause]. And I don't know why, I don't know why, I don't know why, I don't know why [emphasis].' (Jolley, 2004, p. 153)

The caring but affectionless environment is interpreted by the child of the 1920s as inhuman:

'Well there was nobody there [meaning no-one who was human] to ... I might have just been a lump of meat, you know, but don't forget that I was only four and a half, five, but I never saw my parents. And I was terrified of what they [the nurses and doctors] were going to do. [pause].' (Jolley, 2004, p. 148)

These accounts show that children did not have access to their parents and that the staff were construed as being non-human, largely because of an approach that lacked affection. Nurses did care about the children and about their anxieties and fears, but did not show their emotions and hid the affection they had for the children. Jolley's (2004) study shows that the children perceived the nurses as uncaring because they did not demonstrate their affection for the children. Had parents been present, the children's experience of hospitalization would have been entirely changed.

How could these events have taken place in what purported to be a caring environment? The conventional interpretation of this history is that nurses were largely ignorant of the child's developmental, social and psychological needs, and were too highly focused on the child's physical and medical needs. Hospitals at this time were more institutionalized (Goffman, 1962) than is the case now and any attempt at change to make them less so was often organizationally obstructed (Jolley, 2007). However, these explanations fail to account for the kind of nursing to which sick children were exposed during this period of nursing's history.

Early children's hospitals

The first hospital specifically for children opened in 1802 in Paris (*l'hôpital des enfants malade*), followed by others in St. Petersburg, 1834; Vienna, 1837 and London, in 1852 (Lomax, 1996). The early children's hospitals were kindly places (Wood, 1888; Yapp, 1915). Florence Nightingale was keen to portray the nursing of children as a motherly occupation, where affection for the child was overt and unmasked by the nurses' professional orientation (Nightingale, 1886). Prior to World War One, there was an emphasis on the emotional needs of the child. Substantial evidence demonstrates that before the 1920s nurses practiced a form of care that took full account of the child's social and psychological needs (Wood, 1888; Yapp, 1915). However, by the 1920s, this had changed to a more industrialized environment, and hospitals became grim places for children (Jolley, 2004; 2007). Ward routines suited the staff rather than the patients, and parents relinquished responsibility for their child to the hospital staff (Shields & Nixon, 1998).

Nursing between 1920 and the end of World War Two was characterised by the battle of science against infectious diseases and against cross-infection in hospitals. Parents were excluded for fear of them spreading infection (Aubuchon, 1958). The introduction of antibiotics had yet to take place but the threat of infectious diseases was well known. Hospital staff worked in fear of an outbreak of infectious disease which would spread and infect others, might force the hospital to close, and thereby malign its reputation (Lomax, 1996). In the absence of antibiotics, order, discipline and asepsis were matched against the spread of infection, and, perhaps necessarily for the time, were given higher priority than the emotional needs of either children or parents.

Progress to family-centered care

There were isolated examples of practitioners who tried to develop FCC practices in the years between 1920 and 1970. However, these examples were isolated, unrepresentative and un-sustained. In the UK, Sir James Spence established the first mother-and-child unit in 1927 (Spence, 1947, Robertson, 1962) and in the US, infection as a reason to restrict visiting to children was questioned in the 1940s and 1950s (Citizen's Committee on Children of New York City, 1955; Faust, 1953; Fleury *et. al*, 1954). Research from New Zealand showed that infection rates did not increase if parents stayed with their hospitalized infants (Pickerill & Pickerill, 1945; 1946). Psychiatrists began to trace conditions in adults to the childhood experience of hospitalization (Pearson, 1941; Bowlby, 1944a; 1944b). In the US, Renee Spitz (1945) used the term “hospitalism” to denote a decline in health of a child due to long confinement in a hospital. Some described the traumatic effects of surgery on children and alleviation of such effects by involving the mother (Levy, 1945; Powers, 1948; Stevens, 1949). However, it was the cataclysmic events of World War Two which provided the catalyst for change in public opinion which facilitated the eventual implementation of FCC.

World War Two: catalyst for change

World War Two caused people to turn away from the prevailing and relatively hard behaviourist approach to the care of children in hospital that had been prevalent in the inter-war years (Bradley, 2001; Jolley, 2004; 2007). The war had caused much separation from loved ones and much suffering and grief. Thousands of European children were evacuated to the countryside (Crosby, 1986) and abroad (Maunsell, 1940). World War Two brought with it an increasing concern for the psychological

health of both adults and children. In the UK, this new concern was largely the result of the mass evacuation of children (Isaacs, 1941). Hundreds of thousands of children were relocated away from their families and on such a scale that most UK citizens would, in one way or another, have experienced the resulting distress and psychological trauma. Inevitably, psychologists turned their attention to the phenomenon of child-parent separation caused by the evacuations (Burlingham & Freud, 1942), and to other forms of separation such as that which took place when children were admitted to hospital (Bowlby, 1944a, 1944b; Illingworth, 1956; Robertson & Bowlby, 1952). However, nursing and medicine were slow to change, and behaviourism remained the accepted way in which the nursing of children was understood between 1920 and 1970. Nurses were not ignorant of the child's social and emotional needs but were, in fact, practicing the accepted thinking of the day.

Around the world, the first steps toward FCC were faltering and slow. Opposition to parental involvement (Jensen & Colmly, 1948) was reflective of the *status quo* and of popular nursing opinion. Moves to allow parents to visit their children in hospital remained isolated and unrepresentative. An additional problem was the fact that nursing had become unresponsive to change (Walsh & Ford, 1989); there was a 'known way' in nursing that was almost unchallengeable.

The evolution of family-centered care

The changes in the care of children in hospital that saw the evolution of FCC developed largely from the work of two British theorists and investigators, John Bowlby and James Robertson (Bowlby, 1944a; 1944b; 1973; Robertson & Bowlby, 1952, Alsop-Shields & Mohay, 2001). Bowlby and Robertson worked in the Tavistock Institute, a child guidance clinic in London. However, while these men

were hugely influential, that influence was there only because of citizens' readiness to listen to the message. In the UK, and, we suggest, in other countries affected by the war, this readiness to listen was an effect of the experiences of World War Two and especially of the mass evacuation of children.

The work in the US of such researchers as Renee Spitz was complementary to that of Bowlby, and there was much debate between the members of the Psychoanalytical Society, of which both were members, about each other's work (Spitz, 1960). Also enjoined in these arguments was Anna Freud (1960) (Sigmund's daughter) who, with a colleague, Dorothy Burlingham, (Burlingham & Freud, 1942) had run homes in London for children affected by World War Two. They studied the children in their care to determine the psychological effects of separation from their parents, and the effects of war trauma. However, there can be little doubt that of all these researchers, the one most recognised as the theorist who best explicated the effects of separation of mother and child was Bowlby, who became the acknowledged expert (Alsop-Shields & Mohay, 2001). The other person who was effective in this area was James Robertson, who turned Bowlby's theories into practice. He and his wife, Joyce, made films of the effects of separation of parent and child due to hospital admission, and took them to the US, Australia and Europe, showing them in children's hospitals and other places used by parents, such as schools and town halls. Bowlby and the Robertsons, more than any others, can be credited with the beginning of the development of FCC (Alsop-Shields & Mohay, 2001). Bowlby's theoretical work on separation anxiety and grief (Bowlby, 1944a; 1944b; 1973) was well respected at the time, both in the UK and the US (Spitz, 1960). While Bowlby's research might not be considered methodologically sound today, his theory on child separation and grief has survived well. Bowlby's theoretical work still forms the

rationale for today's practice of FCC, which has become one of the core (though unproven (Shields *et. al*, 2007)) philosophical principles of pediatric nursing.

The role of parents in the evolution of family-centered care

Consumers, (largely, in this case, parents) have been influential in improving the care for their hospitalized children. The Citizens Committee on Children of New York City (1955) advocated more “child friendly” hospitals, including allowing parents more access to their children, while the British government in 1959 published a report of an inquiry into conditions in children's hospitals, commonly known as the “Platt Report” (Ministry of Health, 1959). British parents who were committed to ensuring the recommendations of the Platt Report were put in place formed one of the world's first health consumer organisations. What is now Action for Sick Children was formed in 1961 as Mother Care of Children in Hospital (Action for Sick Children, 2006). In 1962, they carried out a survey to determine the level of parental involvement allowed in British hospitals, and were able to influence government as an electoral lobby group. By 1963, 31 member groups had formed across the country, and their first national conference held. In 1965, the association changed its name to “The National Association for the Welfare of Children in Hospital” (NAWCH), and then again in 1965 to “Action for Sick Children” to reflect the growing number of children being nursed at home.

In the US, the Association for the Care of Children's Health was formed in 1965 (Johnson, 1990). Members were health care professionals, not parents or children, as it was feared that if parents became involved, the health disciplines would lose control. Insights by Johnson, one of the founders, question the motivation behind this. In 1978, parents were allowed to join, and the organization produced many

influential initiatives which improved the care of children in health services.

However, in more recent times, the Association for the Care of Children's Health has disbanded (though we could find no evidence of when this occurred). Johnson was instrumental in setting up another organization with similar aims, the Institute for Family-Centered Care, which was begun in 1992 (Institute for Family-Centered Care, 2007). It has had input into many of the major health initiatives in the US since. A prodigious output of documents, position papers and consumer advice publications, as well as an easily accessed web-based service has meant a high level of influence over policy and development of children's health initiatives, in particular those related to FCC.

Other countries have had similar organisations, for example, the Australian Association for the Welfare of Children's Health, begun in 1973 (Australian Association for the Welfare of Children's Health, 2003); Children in Hospital Ireland in 1970 (Children in Hospital Ireland, 2007), and the European Association for Children in Hospital, a blanket organisation in which 16 European countries and Japan have membership (European Association for Children in Hospital, 2006).

The evolution of family-centered models of care

The movement to change the way children were cared for in hospitals had a profound effect on nursing. Initially, nurses were divided in their attitudes. They undertook little research into FCC themselves but relied instead on Bowlby's (1973) and Robertson's (1970) theories. Some nurses were pleased to have parents stay with their children (Fleury *et. al*, 1954), others were not convinced that it was in the best interests of the child (Gofman & Schade, 1957), and some were hostile to the idea (Aubuchon, 1958). Some nurses thought that the parent's presence undermined the

relationship between nurse and child (Frank, 1952), while one study of pediatric nursing care from the period described ways to ameliorate the emotional trauma in children due to separation from their parents, but did not advocate that parents should stay (Godfrey, 1955).

Over time, various models of care developed, such as parent participation, care-by-parent, partnership-in-care, and FCC. These models evolved slowly at first, and largely as a result of Robertson's proselytising, came to be recognised world wide (Alsop-Shields & Mohay, 2001). A loosening of visiting hours was followed by 24 hours visiting by parents, and eventually, an acknowledgement that parents were important participants in the delivery of care to their child (Robertson, 1970). The US led the way for a time with the introduction of care-by-parent units, and these were more slowly adopted by other countries. The care-by-parent scheme offered a complete re-orientation of the concept of responsibility for the child in hospital. Previously, the child had been the responsibility of the nurse and doctor, but with the new ideas, parents retained responsibility for the child whilst still being in the care of health professionals. Care-by-parent units, in which the parents (and family) lived-in with the sick child (Goodband & Jennings, 1992) were first introduced in US in the 1960s, while the first care-by-parent scheme in Britain began in Cardiff in 1980 (Cleary, 1992). In these, the role of the parent is outlined and expectations negotiated on admission. Such units are particularly beneficial for babies who are being breast-fed, and for children with serious and chronic diseases. Such units are equally suitable for children with other, short-term illnesses or surgery, but their set-up costs are high.

Partnership-in-care (Casey, 1995) emerged in the early 1990s, designed by a New Zealand nurse, Anne Casey, working in the UK. It encompasses two principles:

1. that nursing care for a child in hospital can be given by the child or parents with

support and education from the nurse; and 2. that family or parental care can be given by the nurse if the family is absent. The role of the parent is to take on everyday care of the child, while that of the nurse is to teach, support, and, if necessary, refer the family to others. A study which examined parents' views of partnership-in-care found that all viewed their participation as a non-negotiable part of parenthood and intrinsically necessary for the child's well being (Coyne, 1995). The most important part of ensuring successful partnerships with the nurses was the giving of information and using effective communication and negotiation.

Family-centered care appears as almost a natural progression, and has become a by-word in pediatrics, accepted, at least in theory, by most health professionals. It has relevance across cultures. In a large, comparative study of the care of children in hospital in developed and developing countries (Shields & Nixon, 2004), it was found that in developing countries, hospitals thought they were practicing FCC, as parents gave much of the care. However, it was exigencies of the poorly resourced and staffed health services which brought this about rather than philosophical choice on the part of the hospital (Shields & King, 2001).

Implications for practice today

Today, most pediatric health practitioners believe that FCC is the best way to deliver care to children in hospitals and in the wider health services. However, while many say they believe they practice FCC, it is not implemented effectively (Coyne, 2007) and parents are becoming resentful that they are being 'made' to do the nurses' work (Coyne, 1995; Coyne & Crowley, 2007; Darbyshire, 1995). Indeed, this finding effectively demonstrates that FCC, with its emphasis on effective negotiation of roles between parents and staff, is not always implemented correctly. We have no real

evidence that FCC works, or if it makes a difference to patient outcomes for children and families (Shields *et. al*, 2007). Randomised controlled trials of FCC are badly needed, and not until they are completed will we know how best to develop FCC into the future. It is likely that another model will derive from FCC, and the lack of evidence about its effectiveness leaves the field open for new ideas and practices.

Conclusion

The message for today is the same as it was a generation ago. Children need both affection and their parents. It is not too extreme to suggest that children in hospital need a loving environment. Children's medical and surgical needs are, of course, important, but only unusually superordinate. The child's trusting relationship with his or her parents is a thing of great value and a core component of what it is to be a child, and this must be upheld during a child's admission to hospital, or, indeed, any interaction with a health service.

The evolution of FCC through emerging models of care has resulted in changes in practice, and few would argue against the necessity of such changes for the betterment of care of hospitalized children. Nonetheless, its history is more complex than once thought. World War Two was not in our time, but there is a danger in coming to believe once again that the child's medical needs, exigencies of managed care, cost and administrative factors are more important than are the child's needs as a child. Jolley (2004) found that above all else, children need affection, that is, the active demonstration of our love for the child. We should ask why our favourite pediatric textbook does not have a chapter on "affection" and why talk of love in nursing seems to be regarded as less than professional. We have much to learn and much to remember from the past.

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Figure 1. Elements of FAMILY CENTERED CARE as proposed by the Institute of Family-Centered Care (Institute for Family-Centered Care 2007).

- recognizing the family as a constant in the child's life;
- facilitating parent-professional collaboration at all levels of health care;
- honoring the racial, ethnic, cultural, and socio-economic diversity of families;
- recognizing family strengths and individuality and respecting different methods of coping;
- sharing complete and unbiased information with families on a continuous basis;
- encouraging and facilitating family-to-family support and networking;
- responding to child and family developmental needs as part of health care practices;
- adopting policies and practices that provide families with emotional and financial support; and
- designing health care that is flexible, culturally competent, and responsive to family needs.