

Child-Centred Nursing

Chapter 1

Approaches to Nursing Children, Young People and their Families

Key points

- Caring for children, young people and their families requires well developed understandings of the health, psychological, developmental, communication and cultural needs of each child and young person.
- The family is an integral part of how children and young people experience and engage in society and health care.
- Family-centred care and child-centred care are key philosophies underpinning the nursing care of children and young people; however, their application in practice is not without problems.
- Children are not a homogenous group and each child has their own individual perspectives and experiences.
- Children and young people with complex care needs require special considerations to ensure their health, well-being and rights are met.
- Transitioning from paediatric to adult care settings can present issues for young people, their parents and health care professionals.

Key theories and concepts explored in this chapter are child-centred care, family-centred care, children participating in their care and transitioning between services.

Case study 1.1: Mikael

Setting the scene

Mikael is 4 years old and has just been diagnosed with type 1 diabetes mellitus. He lives with his parents, Catherine and John and his two siblings, Sarah aged 1 year and Sam aged 6 years. Mikael is an active, inquisitive child, who is 'into everything'. The

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family moved to the area a couple of years ago, so do not have an extended family support network close by.

Mikael was admitted to hospital in diabetic ketoacidosis and spent two days in intensive care for initial stabilisation. He was then transferred to the children's ward for further care and education. He spent a total of six days in hospital. The time Mikael was in intensive care was a very stressful time for the family and they also needed to come to terms with Mikael's unexpected and new diagnosis of type 1 diabetes. Because of his young age, Mikael will be fully reliant on his parents for the monitoring and management of his diabetes, including initially six finger pricks a day to monitor blood glucose levels, insulin injections morning and evening, his diet and general well-being.

John (Mikael's father) needed to return to work after the first three days of Mikael's hospitalisation. He travels across town to his job and works long hours. This meant that Mikael's mother, Catherine, was taught the skills she needed to be able to care for Mikael and she was expected to teach John these skills. Catherine stayed with Mikael for the first two nights on the children's ward but was not able to stay for the other nights. The family only had one car and so on the last two days of his admission, Catherine and the baby travelled an hour to the hospital by bus after seeing Sam off to school. Although Catherine missed being there for Mikael's morning insulin on these days, she was there during the day to receive education and for his evening dose of insulin. John called in to spend a short but enjoyable time with Mikael before taking Catherine and the baby home, and picking Sam up from a friend's place along the way.

Introduction

This chapter focuses on the philosophical underpinnings of children's and young people's nursing. In the discussion that follows you will be encouraged to reflect on the philosophies of family- and child-centred care, what they mean to you in your practice, the points of tension and challenges that exist, and the care of children, young people and their families more generally. The case study provides a means for reflection on how children and families experience health care and what informs ways of working with them. This includes some of the taken-for-granted aspects of care and also best practice and possibilities for achieving child- and family-centred care.

A number of assumptions underpin the discussion throughout the chapter. Firstly, children and young people experience illness, injury and disability in a different way from adults and their health care needs are therefore quite different to those of adults. Further, children's and young people's developmental immaturity leads to certain vulnerabilities. Their vulnerability is not an inherent consequence of childhood or adolescence as such, but a result of adult-centric social structures and services that children and young people cannot access as easily as adults. In addition, childhood and adolescence are characterised by rapid physical, cognitive, developmental, social and experiential changes. Children's and young people's dependence on adults is naturally on a continuum of dependence to growing independence – although this latter point may not necessarily be the case for children with long-term complex conditions (Children's Hospitals Australasia 2010). Care of

children and young people also involves unique considerations in terms of communication, consent (or assent) and confidentiality (Ford et al. 2007).

Societal and economic impacts provide varying contexts for children's lives in the 21st century. For example, women's increased participation in the workforce and changes to family structures (including the increased numbers of single parent families and of childless families) impact on children within families and in the broader society. Intergenerational relationships also need consideration, particularly with the increasing numbers of frail older people requiring care and support within families and society (Christensen and Prout 2005: 51).

Children and young people experience health care services in many different settings, such as in their homes, their community and in hospital settings. While much of the literature relates to the care of children in hospital, it must be acknowledged that health care for children largely takes place outside of hospital wards and clinics. Caring for children with complex needs within the home, for example, poses different and sometimes quite complex issues about how health care professionals work in family-centred ways (Kuo et al. 2012).

A further important assumption for nursing children and young people is that nurses who provide this care need to have well-developed skills to recognise the particular health, psychological, emotional, developmental, communication and cultural needs of each child and young person (Hill et al. 2011: 80).

An historical context of children's health care

Tracing the historical place in which children and young people have been positioned in health care, whether that care is within the community or in hospital, shows that it has been largely influenced by their positioning within society more generally. The roles families play in their child's health care have also been impacted by social drivers. Advances in preventative health such as the impact of immunisation as well as treatments and technology, policies and legislation (most notably of course in affluent societies) have also shaped how and where children and young people are cared for. Once fatal childhood diseases such as congenital heart defects or leukaemia are now treatable, and many children in countries with appropriate resources can now survive into adulthood (Stang and Joshi 2006).

When considering the history of the care of children in hospital, the 19th and earlier part of the 20th centuries saw parents excluded from the wards and denied the opportunity to be with their child. The understanding at that time was that children in hospital settled better when parents did not visit. During this same period, parents of children with severe disabilities were strongly urged to institutionalise their children, resulting in these 'hopeless cases' being physically removed and separated from their families. The environment considered suitable for the hospital-based care of children has changed considerably since the first wards built for children. Figure 1.1 shows a photograph of a children's ward at the beginning of the 20th century and Figure 1.2 shows architectural drawings of the wards of the 'Hospital in the Park' in Liverpool, UK, which is due to be completed in autumn 2015. These



Figure 1.1 The Verandah, Children's Hospital circa 1910. (Image reproduced with the kind permission of the W.L. Crowther Library, Tasmanian Archive and Heritage Office.)



Figure 1.2 Image of contemporary design for a children's ward. (Reproduced with kind permission of Alder Hey NHS Trust, Liverpool, UK.)

starkly contrasting environments reflect very different ways of thinking about what is necessary to be able to deliver good health care to children.

The hospital rules from a children's hospital in 1947 limiting parents visiting their hospitalised children are presented in Figure 1.3. The strict and inflexible rules outlined here appear similar to those for visiting prison inmates (Street 1992). While the regulations and practices intended to safeguard the best interests of the ill child, such practices did not support the interests of the parent or child so much as institutional interests (Street 1992). For example, medical staff determined how often, and for how long, children might be with their parents.

The strong emotional reactions of children to their parents when they were allowed to visit was seen as evidence that parental visits had a detrimental effect on children's well-being. The recognition that the practice of separating children and parents could cause possible psychological trauma to children who experienced hospitalisation was slow to develop. Following on from societal reactions to the effects World War II had on the separation of children from their families, the subsequent work of people such as child psychologists John Bowlby and James and Joyce Robertson on separation, and reports such as the Platt Report (Ministry of Health 1959), children's health care in the second half of the 20th century saw changes in care practices. As a result, the involvement of parents in the care of their sick child became an accepted feature of children's nursing. In Australia, daily visiting for children was adopted in the 1950s and 1960s and mothers whose young babies were sick were able to be with their children in hospital in the late 1970s (Wood 2008: 123). Sibling visits and parents accompanying their children to theatre were other changes to care practices around this time (Kuo et al. 2012). However, the recognition that the interests of children, young people and families should be at the centre of children's health care was slow to pervade all areas of children's health care.

Patients are not allowed visitors unless they have been in the hospital for a period of four weeks, after which time only the parents or guardians (no friends or relatives are allowed) are permitted to visit on each alternate Sunday in each month, between the hours of 2 p.m. and 3.30 p.m. Parents or guardians of patients dangerously ill are allowed to visit as often as the Doctors consider necessary.

Parents or guardians of patients in the Baby Wards and Infectious Wards are only allowed to visit with the special permission of the Medical Superintendent or his Deputy.

These regulations apply to the hospital section ... and have been made to protect the interests of the patients in the Hospital...

Lollies, Cakes, Biscuits, etc., must not be brought to the Hospital for patients. Raw or dried fruits, nuts, eggs and nourishing foods are of benefit, but must be handed to the Sister of the Ward. (Royal Children's Hospital)

Figure 1.3 Hospital visiting rules 1947 (cited in Street 1992: 11)

The description by Joy Chester – founder of AWCH (the (Australian) Association for the Wellbeing of Children in Healthcare), of her experiences around the admission to hospital of her child illustrates this:

In July, 1969, my 6 year old son was hospitalised at a major children’s hospital in Sydney. I stayed with him for four days. The ward TV-set proudly showed man taking his first steps on the moon, while below it, lonely babies and children cried, rocked or were quietly withdrawn. The contrast of advanced scientific technology and the neglect of the emotional needs of those children was overwhelming. (cited in Wood 2008: 124)

The current context of children’s health care

Despite significant progress and initiatives to address the negative experiences of children who are hospitalised, children continue to experience physical harm, unnecessary pain, fear and anxiety during and after health care experiences (Nicholson and Clarke 2007). A number of reports and inquiries have highlighted continuing deficits in health care services where bureaucratic and systemic interests have been privileged over those of children and young people. In the UK, for example, the Bristol Inquiry Report was instigated in response to the deaths of some 30 to 35 children undergoing cardiac surgery between 1991 and 1995 that were found to be the result of major ‘flaws and failures within the hospital, its organisation and culture’ (Kennedy 2001: 154). The report found that in health care services children were treated as ‘mini adults’, simply needing ‘smaller beds and smaller portions of food’ and that information was not provided in a suitable form for children or their parents. Further, it was reported that staff did not have specific education in caring for children and that the facilities did not meet the special needs of young children, older children, adolescents or parents (Kennedy 2001: 12). The Garling Report (2008) was conducted in the Australian state of New South Wales and included a review of health care services for children and young people following adverse events that shocked the public, including the death of a young person whose care was found to be inadequate. These reports and others have led to significant policy and practice changes that emphasise the importance of placing children, young people and families at the centre of care. Many policies that have been developed for the standards and rights of children’s and young people’s health care are framed by the United Nations Convention on the Rights of the Child (UN 1989) that encapsulates the universal rights of children.

The UN Convention on the Rights of the Child (UNCRC) was adopted by the United Nations General Assembly in 1989. It acknowledges the status, role and rights of children and their needs and situations by setting standards in health care, education and legal and social services (UN 1989). Articles of the Convention that directly relate to health care are outlined in Table 1.1. National and international standards for health care aim to achieve child-centred health services and are underpinned and

Table 1.1 Articles of the UN Convention on the Rights of the Child that relate directly to children's health care (Nicholson and Clarke 2007)

Article	As the Article relates to health care
2	Equal rights to care with no discrimination for any reason
3	Whenever an adult makes any decision about a child or takes any action that affects the child this should be what is best for the child
6	The right to live
7	The right to name and nationality, and to be cared for by parents
9	The right to remain with parents, or in contact with parents, unless this is contrary to the child's 'best interests'
12 and 13	The right to receive information and express views and ideas freely
19	The right to be protected from any form of harm, including violence, neglect and all types of abuse
23	The right of those with a disability (physical or mental) to lead a full and decent life within their community
24	The right to the highest standard of health and medical care attainable
27	The right to a standard of living adequate for physical, mental, spiritual, moral and social development
28	The right to education
30	The right of a child belonging to an ethnic, religious or linguistic minority to enjoy their culture, practise their religion and use their language
31	The right to rest and play
38	The right to be protected from and during armed conflicts, and not to be recruited to take part in hostilities, especially before the age of 15 years
42	Is about the duty of the state to ensure that children's rights relating to health are made known

informed by the UNCRC. As an example, the World Health Organization's Child Friendly Healthcare Initiative (Southall et al. 2000) aims to achieve internationally applicable standards for practices in hospitals and health centres. The health care standards proposed in the initiative are based on children's rights as expressed in the UNCRC.

The Australian National Standards for Children and Adolescents in Health Care (RACP 2008) also reflect the rights of children as outlined in the UNCRC and aim to ensure quality care for children and young people in an environment that is 'safe and appropriate for the age and stage of development of the child or adolescent' (RACP 2008: 3). In addition, these standards recognise the special health care needs of children and young people; that they need to be cared for by specially trained staff; and that children require separate facilities in all areas of

the health care service where they are cared for (RACP 2008). The European Association for Children in Hospital (EACH) is another example of an organisation concerned with children's health care. EACH is the umbrella organisation for 13 national associations in Europe involved in the welfare of all children before, during or after a stay in hospital. EACH was established to promote the implementation of the European Charter for Children in Hospital and the 10 principles of the EACH Charter relate in many respects to the rights of the child as outlined in the UNCRC.

As a result of such initiatives, children's contemporary experiences of health care are different in many ways to those of earlier times. These changes manifest the rights of children as outlined in the UNCRC (UN 1989). For example, the child's right to remain with their parents is expressed in Article 9 of the Convention, and one important feature in contemporary children's health care is increased parental presence and support. Hospital rules that once limited parental visits have (although we would argue – not universally) been replaced with policies that support parents residing in hospital.

Family-centred care

When I got to hospital it was good to have dad there. Mum had to stay home and look after my big brother. (11-year-old boy, Ford 2010)

The case for working *with* children, young people and their families is now recognised as fundamental to the care of children and young people. Children are dependent on their families in all aspects of their daily lives and it is the context of family that is most instrumental to children's and young people's growth and development (Children's Hospitals Australasia 2010). It makes sense that the nursing care of children, young people and their families places their interests at the centre of their care. Family-centred care (FCC) is the most common philosophical approach underpinning health care delivery for children and young people in Western countries such as the UK, Australia, New Zealand, the United States and Canada. Since its inception FCC has had various forms and its definitions have evolved with time. However, in essence FCC is a way of working in partnership with a family. Essentially FCC recognises that children need to be cared for in the context of their family and that the family is both the constant in a child's life and should be central in the child's plan of care (Ahmann 1994). The philosophy of FCC, in effect, intends a more equal partnership between the health professional and parent in the health care of the child. Principles of FCC (based on those developed by American organisations including Family Voices and the Institute for Family- and Patient-Centred Care) are presented in the Table 1.2.

The more recent definition of FCC by Shields et al. (2006) recognises all the family members as care recipients, because when a child is admitted to hospital, the whole family is affected. FCC should inform the health care of children in their homes and in other community settings. Shields et al. (2006) describes FCC as a way of caring for children and their families within health services that ensures care is planned around the

Table 1.2 General principles of family-centred care (adapted from Kuo et al. 2012: 298)

Information sharing	The exchange of information is open, objective and unbiased
Respect and honouring differences	The working relationship is marked by respect for diversity, cultural and linguistic traditions, and care preferences
Partnership and collaboration	Appropriate decisions that best fit the health care needs, strengths, values and abilities of all involved are made together by involved parties, including families, at the level they choose
Negotiation	The desired outcomes of care plans are flexible and not necessarily absolute
Care in the context of family and community	Direct health care and decision making reflect the child within the context of his/her family, home, school, daily activities and quality of life within the community

whole family, not just the individual child/person. A family-centred approach to children's and young people's health care recognises that their emotional and developmental needs as well as overall family well-being are best achieved when the system supports the abilities and choices of the family to meet the needs of their child (Shields et al. 2008).

Family structures in Western societies are increasingly complex and dynamic. Families can include blended families, single-parent households, adoptive homes, same-sex couples, and members of the extended family. A family-centred approach recognises diversity among families including family structures, backgrounds, goals, strategies, actions and strengths. It includes respect for personal and cultural beliefs and the importance of incorporating these beliefs into health care choices. Such an approach also recognises that families experience differences in family support and service delivery and have different information needs.

Case study 1.2: Mikael

Planning and caring for all the family

Care for Mikael's diabetes must involve his family as it will have impacts on all family members such as influencing their food choices and the timing of family meals. Mikael's family was advised that they should all eat together and have the same foods, rather than preparing 'special' food for Mikael. The Diabetes Nurse Educator (DNE) knows that, as the family learns to manage and to live with Mikael's diabetes, there will be a strong focus on this new aspect of his life and theirs.

Catherine cares for the children during the week and John is the primary carer at the weekends when Catherine is at work. This employment pattern reflects shifts in family structures and functions in Western society which means that fathers may not be the

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sole 'breadwinner' in a family and parents often share direct parenting responsibilities. John needs to be able to manage Mikael's care at the weekends, including giving him his morning insulin and preparing meals.

When providing Catherine's education, the DNE assessed Catherine's confidence and skills in being able to manage Mikael's diabetes regime and used a number of supports to help her, including written material, experience in administering insulin to Mikael with supervision as well as using skin models to practise on. They also talked about the different 'diabetes scenarios' that might occur and how these could be managed. These scenarios included what to do if Mikael's blood sugar drops too low, what to do if the insulin vial is dropped on the floor or what to do when Mikael has a 'sick day' (is unwell). The DNE also worked to ensure Catherine could teach these skills to John.

The DNE encouraged Mikael to participate in his care as much as possible, by giving consideration to his individual development and abilities. Although he protested about the needles, his parents were advised to take a positive approach to Mikael's involvement and the treatment. So they encouraged him to be involved by washing his hands, doing his finger pricks and taking part in choosing the injection site. In time, as he became more accepting of the injections, he also pushed the plunger on the syringe.

The DNE was aware from the start of Mikael's care that the inclusion of his siblings also needed consideration. When Mikael was first diagnosed, 6-year-old Sam was frightened that Mikael was very sick in hospital and that he might die. The DNE suggested that Catherine brought Sam to the hospital one afternoon to see and to play with his brother. The visit alleviated his fears and the nurses on the ward provided Sam with age-appropriate information about Mikael, explaining that Mikael had a medical condition and he needed to have special medicine to keep him safe. Mikael and Sam played a game together and Mikael showed Sam how he did his own finger prick and how it did not really hurt.

Family-centred care and children and young people with complex needs

Children are not a homogenous group, and children and young people, such as those with disabilities, those in out-of-home care, those from culturally and linguistically diverse backgrounds and refugees require additional services to address their specific needs (Children's Hospitals Australasia 2010: 6).

Children with complex needs are a broad group of children with very diverse needs, including those children requiring long-term ventilator support, children needing assisted enteral or parenteral nutrition, children requiring administration of intravenous medication, children with mobility or sensory impairment, children with behavioural needs and children with life limiting or life threatening conditions. Increasing survival rates for children with complex conditions and for those born prematurely means that the numbers of children in this group is growing.

Children with complex care needs require increased health services beyond those generally required by healthy children. Frequently their health care needs are inextricably part of their everyday lives and treatments and technologies may overlay and

dominate their lives and have a profound impact on other family members such as their siblings. However, despite these differences, many children with complex care needs have the same wishes and needs as other children. Things that matter to them include living at home, going to school, spending time with friends and participating in recreational and community activities with family and peers, and these things are also important to their families (Social Care Institute for Excellence 2008). Woodgate et al. (2012) explored the impact that caring for a child with complex needs has on parents' and families' levels of participation in everyday life. They referred to the notion of 'having a life' which entailed feelings of belonging, of being accepted and being able to contribute to the spaces they participate in. This sense of having a life required access to resources and significant 'physical, mental, psychological and spiritual work' by parents, that was sometimes found to be very difficult to sustain.

Children and young people with complex health needs and their families often require high levels of physiological, psychological and social care that brings them and their families into contact with a wide range of services; health care professionals are but one group among many (Carter et al. 2007). There is a recognised need for a 'seamless web' of care, treatment and support and for real partnerships between health and social care agencies that includes the child or young person and family as integral participants. However, while this seamless web is the ideal, studies demonstrate that families' experience of services is often not seamless (Carter et al. 2007) and they may not be treated as equal members in the partnership because 'experts' exert their power. Yet despite these challenges, many parents of children with complex needs very quickly become the experts in caring for their child and, as previously recognised, they are often expected to act in this role. The notion of how children and young people live with special or complex conditions will be explored in more detail in Chapter 5 of this book.

Family-centred care: the case for and against

While children's nurses generally espouse the philosophy of FCC for all children and families as the ideal approach to care, effective collaboration and the meaningful involvement of families may, in fact, be quite challenging to achieve. FCC is a complex and sophisticated relational dynamic that is influenced by a number of internal and external factors (Carter 2008). The case for and against FCC needs to be considered carefully, as do the possible ways forward.

The case for FCC as a fundamental premise is a strong one. FCC, in its different forms as a way of working and being with families, has been fairly universally embraced by practitioners, educationalists and researchers for more than 50 years (for example, *The Platt Report* in the UK (Ministry of Health 1959) and Australian Paediatric Association (1958, cited in Hill et al. 2011)). This is certainly the case in many so-called 'developed' countries such as UK, USA, New Zealand and Australia, as well as in less well resourced countries. FCC presents a way of approaching caring for children, young people and their families that nurses recognise as important. Nurses also find it a satisfying and rewarding way of working (Carter 2008), and the concept of FCC as an approach for working with families is supported by health

care institutions as well as service user groups representing children's and parents' interests (for example AWCH; NAWCH; Institute for Patient- and Family-Centred Care). Yet, tensions exist in the ways that FCC is realised in practice and FCC continues to be inadequately and only partly implemented in clinical practice (Kuo et al. 2012). The complexities and discordances in understanding and expectations of FCC in relation to parent participation have been identified in a number of studies (Coyne and Cowley 2007; Darbyshire 1994; Power and Franck 2008). In addition, there is little evidence around the attainability of FCC as a model for health care delivery.

A systematic review of qualitative studies (Shields et al. 2008) indicated that there was a paucity of evidence around FCC and its effectiveness. FCC was found to be problematic due to the difficulties and barriers such as relational and attitudinal issues that compromise the effectiveness and implementation of FCC – in its fullest sense – in daily practice. It is also recognised that there has been a lack of attention to the skills, support and resources nurses need to enable them to practice in family-centred ways (Barnsteiner et al. 1994: 36). The leadership and culture of an organisation are other factors important to the effective implementation of this model because systemic processes, both overt and implicit, that support the child and family being at the centre are essential. Mikkelsen and Frederiksen's (2011) concept analysis concluded that FCC is only a 'partially mature concept' (p. 1159) and that the 'perspective of the ill child is not very prominent in the current conceptualization of FCC' (p. 1160). As organisations and settings for children's health care change, with a shift from inpatient to ambulatory care, there are additional and new challenges for the provision of FCC.

There is a general recognition that children's admission to hospital should be avoided wherever possible, because of the negative impacts hospitalisation has on children emotionally, psychologically and developmentally, as well as the potential physical risks to them. When a child's admission to hospital is necessary, admission should be for as short a time as possible. The resource costs associated with hospital care, technological advances and economic imperatives have also influenced this shift, so that increasingly out of hospital care is a feature of children's and young people's health care. However, shorter admission times to hospital means that time for the nurse to get to know the child and family can be limited (Ford 2011). Quicker throughput means that time for preparation, finding out about individual family needs and preferences as well as the provision of information about care following discharge are also limited. For example, research around the post-discharge care needs for families (Ford et al. 2012) following the child's admission for surgery has highlighted that while many families receive the information they require to manage care of the child following discharge, this is not always the case. This lack of information then impacts on symptom management, for example the prevention and treatment of pain. An example of one initiative by nurse researchers to provide alternative information sources to improve symptom management after short-stay surgery is the development of online resources with parents for parents (<http://www.mychildisinpain.org.uk/>).

Even when health professionals believe that family-centred care is a central value within their care practices, families may not always see this as the case. A study of FCC practices within a paediatric intensive care unit in Canada (MacDonald et al. 2012) questioned the integration of family-centred care practices into the sociocultural context of a paediatric intensive care setting. Findings indicated that there was a divergence between espoused FCC practices and the lived experiences of family members. The researchers suggest that these structures transform the child into a medicalised object – ‘the patient’ – and the parents are displaced to being the ‘visitor’. While staff made efforts to personalise bed spaces with items such as the child’s own toys or photos, these spaces, in fact ‘belonged’ to staff and parents struggled even to find room to be with their child. Whilst Roets et al. (2012) note that managers need to take responsibility for ensuring the emotional support of parents as part of FCC within the paediatric intensive care setting but equally, all nurses have a responsibility for caring for parents.

We suggest that in considering the role of parents and family, nurses need to reflect on how parents and other family members are positioned. As an example, parents and family members might be referred to as ‘visitors’ in the hospital setting. Even the use of terms such as ‘open visiting’ for parents in ward information sheets carries with it connotations about the role parents are allocated. MacDonald et al. (2012) propose that in using such language, family members are relegated to a role that does not recognise their centrality and that when parents are present with their sick child, rather than visiting, parents are in fact *parenting*.

Whilst parents in general want and expect to participate in their child’s hospital care, the level of parental involvement may be vexed and contentious. There is evidence that parents in contemporary paediatric settings feel increasingly pressured to participate in their child’s care, taking on responsibilities that may traditionally be seen as ‘nurses’ work’ (Coyne and Cowley 2007). Parents are increasingly asked or expected to be involved in more complex responsibilities such as monitoring and coordination roles. This is seen to correspond with an increasing expectation by nurses who take parents’ participation for granted (Coyne and Cowley 2007; Shields et al. 2006). However, the increasing expectations placed upon parents have been found to some extent to be resented by them (Power and Franck 2008: 637). This situation might indicate that, under the guise of FCC, institutional interests have taken precedence over what is in the interests of children, young people and families themselves and that health care practices may not be supportive of their needs. Parents of children with complex needs often perform a number of roles in caring for their child – being a parent and providing skilled ‘nursing’ care in addition to organising services and advocating for their child. There is, in fact an expectation that parents will undertake the role of health care provider, taking on care giving tasks outside of the ‘normal’ parenting role that were previously only undertaken within the domain of hospitals or other health care settings (McCann et al. 2012: 20). Many families experience significant care and financial burdens, including out of pocket expenses, care coordination and income loss (Kuo et al. 2012).

According to Shields (2010), FCC should not be about parents feeling pressured into undertaking all or part of the care for their child if they do not wish to, or if they are not able to. Parents should not be made to feel guilty when they do not undertake all or part of their child's care, whether this is out of choice or ability. FCC *is* about effective communication and negotiation with parents about their level of involvement and participation in their child's care: about what parents want to do and how capable they feel about undertaking aspects of care; about how often and how long they will be present; and the level of involvement they choose for active participation in decision making about their child's care (Shields 2010).

Family-centred care: where to for nursing children and young people?

Any suggestion that FCC should be abandoned as a way of working with children, young people and their families presents both moral and ethical challenges. Clearly barriers exist to implementing FCC in its fullest sense, yet surely it is something we should strive to achieve in our everyday practice as well as in the policies and guidelines that inform practice.

While caring relationships may be problematic, little is known about the meanings FCC holds for children's nurses. FCC as a philosophy of care originated in what Schön (1983: 42) described as the high, hard ground of research-based theory and technique. Application of the theoretical constructs of FCC in the 'swampy lowland' of practice has been shown to be problematic. What is required then if, in its ideal form, FCC is unachievable and cannot be implemented (Carter 2008)? Scholarly literature has a tendency to be dominated by the depersonalised, authoritarian voice and a negative or 'deficit view' of practice (Benner and Wrubel 1989: 395) that serves to limit and close discussion. One way that this distortion can be limited and congruence brought to the rhetoric of the literature around FCC and the realities of practice is through open dialogue. The challenge for children's nurses is to critically reflect on their practices and to engage in dialogue about their values, what underpins their care and how that is realised in practice.


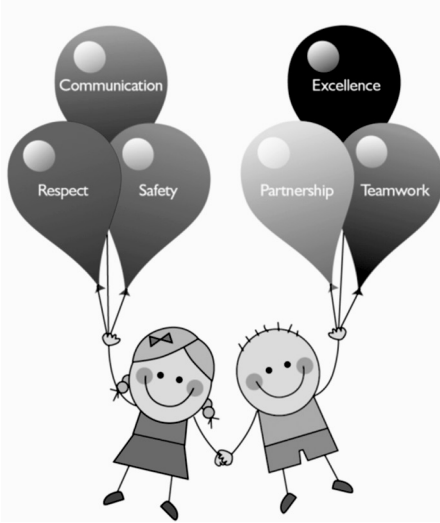
A Practice Development Exercise by nurses on a paediatric unit in Australia has involved the nurses coming together to develop their values and what that means for their way of working together and with children, young people and families in child- and family-centred ways. The unit values include respect, communication, safety, partnership, teamwork and excellence (see Figure 1.4). The values are posted in a central area of the ward for all to see. More than this, however, there is discussion about the values in the nurses' everyday work, and the experiences of children, young people and families as compared to the values are actively explored. Children, young people and families have been surveyed and questions in the survey directly linked to the unit values. Findings from the survey have allowed the nurses to reflect on aspects of care

that are positive and where experiences of children, young people and their families are congruent with the espoused values for family- and child-centred care. Nurses have also reflected on experiences that are less positive and where they may improve practices in order to improve the experiences of children, young people and families. Children's and parents responses to a survey provided important feedback to the staff about the views of those they care for in relation to the unit's espoused values of working with children, young people and their families in child- and family-centred ways. Areas highlighted in the work included communication and information, inclusion in care, opportunities for rest, activities and the physical environment. The work provided staff with an increased awareness of the needs of the children, young people and families, placing their interests at the centre of practice, and translated into a number of changes in response to their experiences, summed up in a quote from one nurse:


I feel it helped us to really focus on the practical and simple changes we can make in our work to make this unit a better place for us, our patients and their families.

Welcome to the Paediatric Unit

Working together to deliver excellence in care for children, young people and families

Paediatric Unit Values Statement



Working together to deliver excellence in care for children, young people and families

- We value respect for colleagues, patients and families.
- We are welcoming, approachable and friendly to children, young people and families in our care; and all who work here.
- We provide clear and open communication about patient care with the family and the multidisciplinary team.
- We ensure continuity of care through effective communication.
- We recognise, assess and relieve the physical and psychological pain and discomfort of children.
- We value the need for continuing education for all health professionals.
- We provide each other with constructive feedback and share our knowledge and skills.
- We ensure that children and their families receive evidence based care.
- We support each other to carry out our work.

Providing care in a safe, child friendly environment

- We enable children to play and learn.
- We support all staff to work within their scope of practice.
- We abide by safe standards of practice.
- We practice within a safe environment that is clean and well organised.

Providing equity of care and recognising children's rights

- We believe children have the right to be treated as individuals without discrimination by providing culturally and developmentally appropriate rights to privacy, dignity, respect and confidentiality.

Working in partnership with children and families

- We share a responsibility to keep parents and children fully informed and involved in all decision making.
- We provide non-judgemental care recognising diversity of values.
- We support families to participate in their child's care to the extent that they are willing and able.

Advocating and promoting children's health

- We support children and their families by promoting health.
- We advocate for the best possible care for children and their families.
- We are a voice for children and their families.






Figure 1.4 Unit values developed in a Practice Development Exercise considering family- and child-centred practice

Reflective prompts: TED 1.1

Think about whether aspects of your practice are underpinned by any beliefs, traditions or ways of working that may not be based on evidence.

- Observe how families are included in the planning and implementation of care as well as in decision making. You might observe a bedside handover, a home visit, a case conference or a consultation.
- What do you think about FCC?
- Where have these beliefs come from?
- How do you think these beliefs shape the way that you practise?
- What did you learn from observing your practice setting?

Explore and evaluate the evidence, perspectives and strategies you have read in the literature and in policy and other documents.

- What policies are in place in your practice setting to support children, young people and their families? For example, you might want to evaluate the arguments underpinning:
 - whether siblings as well as parents should be able to reside in hospital.
 - how you might facilitate families taking meals together in hospital?
 - how you might lobby for the provision of subsidised parking for families visiting their child?

Decide, based on your reflections, how you could improve your practice. Discuss your findings with your colleagues.

- Having reflected on FCC, how could you enhance or improve the way in which you care for, engage with and involve families?
- What are your top three priorities?

Child-centred care: a further evolution in children's health care

Traditionally, the recognised active members of the partnership in FCC have been the health professional and the parents or carers, with the child or young person being allocated a more passive role. Yet the increasing recognition of children's active agency and right to participate has meant that we need to include children and young people as equals in the partnership, so that the notion of the child 'in family' rather than the child 'and family' may be the most appropriate way of conceptualising the relationship. This notion also resonates strongly with family systems nursing that focuses on the whole family unit when providing care (Wright and Leahey 1990). According to Wright and Leahey, who are credited with the presentation of the theory of family systems nursing, the '[c]oncentration is on both the individual and the family simultaneously... It is not "either/or" but rather "both/and"' (Wright and Leahey 1990: 149).

Child-centred care (CCC) means that children and their interests need to be at the centre of our thinking and our practice (Carter and Ford 2013). CCC also refers to the inclusion of children and young people as active participants in their care. CCC can be considered a further development in the on-going evolution of FCC or as an extension of the concept of FCC. According to Franck and Callery (2004: 269) the difference between FCC and CCC is one of emphasis and reflects the extent to which children's concerns are evidenced in the organisation of care. However, neither approach can exclude the other because CCC must take into account the social context in which children live, and FCC must have the health of children as a central concern. CCC acknowledges children as social actors in their own right. An important underpinning premise of CCC is the recognition that children's views are not always the same as those of their parents or of their health carers and that, when given the appropriate opportunities, children are able to represent themselves. FCC can mean that the child's voice is subsumed within that of their family's because professionals may assume that there is a shared family interest. However, this can present difficulties where this is not the case, such as when the child has a different viewpoint to the parents or in cases of child neglect or child abuse.

In contrast to traditional definitions of FCC, in CCC the child or young person is clearly positioned as a key and active member of the partnership. Underpinning this approach is the premise that the best interests of the child or young person must be the paramount consideration. Further, in a child-centred approach, health care professionals recognise children and young people as individuals with their own needs and rights to privacy and dignity, involving them in decisions affecting their care (Southall et al. 2000). Importantly, CCC still recognises the central role of parents and families in relationships and interactions with health care professionals, as evidenced in the examples for ways health services can be child centred (Figure 1.5). Work by Pritchard Kennedy (2012) shows how children in the study were clear that they wanted to develop their competence and become partners in care and in decision making.

As previously mentioned, it is also important to recognise the diversity and individuality of different childhoods and that children and young people are not an homogenous group. There is not one voice that speaks for children and young

- Consider the 'whole child', not simply the illness or condition
- Treat children as children, and young people as young people
- Be concerned with the overall experience of the child and family
- Treat children, young people and parents as partners in care
- Integrate and co-ordinate services around the child's and family's particular needs
- Graduate smoothly into adult services at the right time
- Work in partnership with children, young people and parents to plan and shape services and to develop the workforce

Figure 1.5 Principles underpinning child-centred health services (Department of Health 2003: 9)

people, nor is there one authentic account of children's lives, but rather there exists a diverse range of accounts (Christensen and James 2008). Children's lives, identities and experiences are shaped by many factors including age, gender, life experience, health, family background and friendship groups, school or nursery and their social, cultural, religious and economic situation (Carter and Ford 2013). In addition, children and young people face different opportunities and constraints and have different interests and preferences. For instance, in recognition of the specific cultural considerations of Maori Tamariki (children's) and Rangatahi (young people's) rights in health care, *The Charter on the Rights of Tamariki Children and Rangatahi Young People in Healthcare Services in Aotearoa New Zealand* (CHA and PSNZ 2010) recognises that while services are the same for every child and young person, specific actions are needed to address disparities in access to care.

Health care has been one of many contexts where children and young people have been denied rights of participation and their voices have gone unheard (Christensen and James 2008). Traditionally children and young people have been considered to lack expertise, experience, competence and capacity to be meaningfully engaged in their health care. Paternalistic attitudes where children are viewed as *becoming* (that is growing into adults), dependant, vulnerable and in need of protection can, in fact, result in their overprotection, disenfranchisement and exclusion. The meaningful and active involvement of children and young people in their health care through participation in choices and decision-making is something we are moving closer to achieving, rather than a space where we have truly arrived.

At the start of the values work described in Figure 1.4, it would not have been uncommon for the nurses just to survey parents' perspectives while not considering the perspectives of children and young people themselves. However, through reflection on their values the nurses on the unit enhanced their child-centred practice and now actively seek the voices of children and young people out of a concern to explore the children's experiences and the need to include them as well as parents as active and full partners in care. Children's and young people's responses reflect their own experiences of hospital; in the following examples issues of being bored and wanting choices are presented:

This is my 3rd time in hospital in a couple of months in a way I would like more choices in meals or drinks. It would be good if rooms were sound proof. It can get boring really easily (13 years, 5 months)

On the weekend I was bored but during the week I wasn't as much and there were more things to have fun with but they had to give me blood tests during the night (8 years)

Seeking the views of children and young people meant that their perspectives were heard, acknowledged and acted upon (where possible, given institutional or resource constraints). Their comments highlighted some areas of concern for them that were not necessarily noted by their parents, for example their comments regarding food choices and activities were not reflected in parents' responses.

Reflective prompts: TED 1.2

Think about whether aspects of your practice are underpinned by any beliefs, traditions or ways of working that may not be based on evidence.

- What do you think Mikael's involvement should be in relation to his care?
- Where have these beliefs come from?
- How do you think these beliefs shape the way that you practice?
- To what extent do you think you genuinely enable young children's active participation in their care and decision making?
- What did you learn from considering this scenario?

Explore and evaluate the evidence, perspectives and strategies you have read in the literature and in policy and other documents.

- What literature has informed your thinking?
- How does the contemporary literature differ from the literature published 15 years ago?
- What policies guide your practice and are they informed by contemporary thinking about participation and decision making?

Decide, based on your reflections, how you could improve your practice. Discuss your findings with your colleagues.

- Having reflected on the underpinning values of FCC and CCC, how do the approaches help you enhance or improve the way in which you care for, engage with, and involve children and young people and their families?
- Based on your thinking, what are your top three priorities and how might you ensure that these are achieved?

Child-centred care in practice: how are we doing?

Although the standards cited in this chapter endorse children's and young people's participation in their health care as social actors in their own right, research indicates that children in many instances continue to have a marginal role in such processes (Coyne and Harder 2011: 313). Children's participation in decision making, choices and management of their care is the focus of Chapter 4.

Despite significant gains in children's hospital care since the last half of the 20th century, there is evidence of recent trends to reduce paediatric services. Even when separate facilities are provided, insufficient staffing and resources might mean that children are cared for alongside adults. For example, in Australia, where standards for the care of children and young people are in place, the co-locating of children alongside adults is common and often routine, despite evidence that this is not in the interests of child or adult (RACP 2009). Most paediatric emergency hospital presentations are to Emergency Departments in general hospitals, where children account for 20–30% of the total population of patients. A 2004 national survey of Australian health

care settings found that some 35% of hospitals did not routinely accommodate children and young people separately from adults. Further, since 1992, the number of dedicated paediatric units had decreased by 30% (Hill et al. 2001: 81). Evidence would suggest that this situation has not changed since the survey was conducted. In Canada, only two of the 16 children's hospitals are now free standing following merges with adult or maternal facilities, a move that has been largely due to rising health care costs, rather than being specifically aimed at improving services for children (Stang and Joshi, 2006). These disturbing trends indicate not just a lack of progress towards child-centred health care services but, in some instances, a decline in such services.

Transitioning care: another consideration in the care of young people

As they mature children are expected to take on increasing self-care responsibilities and autonomy in relation to their health care. Being confident about self-care is of particular importance when young people with chronic conditions prepare for and move across to adult services. A strength of child-centred care, when it is working well, is that it can provide opportunities for young people to develop skills and competence to enable them to transition effectively. The best transition practices are underpinned by a collaborative, coordinated and integrative model that empowers young people and their carers. Structured transition programmes do occur but these are often confined to larger specialist settings. However, Doug et al. (2011) note the lack of an evidence base in most of the guidelines used to underpin the development of transition services. In work by Allen et al. (2012) a range of seven different 'continuities' – relational, longitudinal, management, informational, flexible, developmental and cultural – were identified as necessary to support smooth transition.

Improvements in technology and care mean that significant numbers of children with chronic conditions survive to adulthood, and transitioning from paediatric to mainstream adult services is an important milestone in the life of the young person. The transition from child/family-centred health care services to adult-oriented health services can present a challenge for young people and their families as well as for health professionals who provide care to them. This transition is not just an administrative event where a young person's patient file is handed over, but is in fact a complex undertaking that also needs to be a guided educational and therapeutic process (Department of Health WA 2009). Child-oriented and adult health systems are by their very nature quite different. Constraining factors that act as barriers to transition can include lack of infrastructure and precedence, lack of developmentally appropriate support and additional financial costs (Bennett et al. 2005: 373; RACP 2010). Paediatric services may 'hold onto' patients because of mistrust of adult services or because of a failure to promote a young person's independence and autonomy in health-care seeking. In addition, paediatric services are family-focused, while adult services treat patients as independent adults and are less engaged with the

wider family. This is problematic for young adults who still require family involvement because of the nature or severity of their condition or disability, or indeed because this is their choice. Allen et al. (2011: 1000) talk of interdependencies between young people and their parents and of 'how service structures are failing to accommodate the fluidity of cross-generational relationships ... [and the need to] develop service structures that recognize the continuing role played by mothers in supporting their child with diabetes into early adulthood'.

As a result of the barriers that are in place in some settings, some young people and their families may experience stressful and difficult transfers to adult care. These arise when the transition is abrupt, unplanned or delayed so that they continue to be cared for in paediatric services for longer than appropriate.

Conclusion

It is evident that the full participation and involvement of children, young people and their families in the planning and delivery of their care requires careful attention and on-going commitment by a wide range of people including health care professionals, policy makers and commissioners of services. Health care services need to be designed around and responsive to the needs of children and young people, and one way of moving closer to this is to see health care services through their eyes (Department of Health 2003). The findings from the Bristol Inquiry are a clear and sharp reminder of what can happen when children become the objects of care and when the interests of children and families are not given primacy over institutional and bureaucratic interests.

One of the aims of this chapter has been to challenge your thinking through the questions and arguments presented, in order to encourage you to reflect on your nursing care of children and young people. Nurses caring for children and young people are in a position to open up or close off opportunities for them and their families to be active participants in their health care, including their participation in decision-making processes.

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