



HSN7038: Perspectives of Family Centred Health & Social Care (2211_SPR)

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Abstract

Family-Centred Care (FCC) represents a structure that offers enhanced healthcare decision-making as a result of enhanced collaboration and information between families and professional healthcare providers. Achieving this requires training, education, and support, which would ensure that all healthcare providers and staff have a shared understanding of FCC practices. The various healthcare service providers and institutions within a single geographical zone can participate in this program to improve the level of cooperation between them. Therefore, this paper conducts a critical examination of the FCC approach with a particular emphasis on the way the FCC influences the practice in Paediatric Intensive Care Units (PICU). Families are central to children's lives and FCC is an approach that recognizes this fact; thus, allowing families to engage in their children's treatment on an equal footing and ensuring the best possible results for children, families, and the institutions providing care. Along with a review of this field's studies, this paper discusses the way the FCC theory came to be developed and the reason behind its significance. This paper also refers to a case study to better understand the way to effectively apply FCC in practice while avoiding the obstacles that may arise.

Keywords: Social Care, Family Centred Health, HSN7038, Perspectives, Saudi Arabia.

INTRODUCTION

It is stressful for both the patient and the family when a child has to be admitted to a Paediatric Intensive Care Unit (PICU). The majority of pediatric deaths in hospitals occur in PICUs, and regardless of the outcome, families may feel anxious and fearful about their child's health (Abdelkader et al., 2016). Parental role dissatisfaction and poor communication from healthcare teams are also contributing factors to parental distress.

Richards et al. (2017) noted that this can cause long-term psychological effects, and there is a link between the stress parents are under and their child's long-term mental health. Family-Centred Care (FCC) is a partnership approach to pediatric care that encourages parents to take an active role in their child's care.

Richards et al. (2017) also showed that it is 'an important contributor to addressing family distress and improving long-term outcomes of children and their families'. FCC is also one of the most important indicators of contemporary paediatric nursing, and it has received a great deal of attention in the literature (Richards et al., 2017). Abdelkader et al. (2016) highlighted that FCC recognizes the importance of the family in a child's life and encourages parental participation in paediatric care based on the individual needs of the child and their family.

This paper will conduct a critical examination of the FFC approach, with a particular emphasis on how it influences practice in PICUs. Families are central to children's lives, and FCC is an approach that recognizes this fact, allowing families to participate in their children's hospitalization on an equal footing and thus ensuring the best possible outcomes for children, families, and the institutions providing care.

Along with a review of the literature, this paper will discuss how the theory of FCC came to be developed and why it is significant. This paper will also refer to a case study, in order to better understand how to effectively apply FCC in practice while avoiding the obstacles that may arise.

LITERATURE REVIEW

Understanding the Family-Centred Care (FCC)

The term FCC is a common one in paediatric health facilities. In these care settings, treatment plans must be tailored to the children admitted and take into account the values, preferences, and beliefs of their families. This is especially important when a child has experienced trauma, as their family will play a crucial role in supporting their well-being (Jolley and Shields, 2009, Shields, 2015).

FFC shares commonalities with several other terms, for example, 'parental participation', which means that parents who accompany their child to the hospital will be involved in some aspects of their child's care (Chattu and Kumar, 2018). Another related term is 'care-by-parent', which describes the creation of a home-like environment where parents and their unwell child can feel comfortable. In addition, the term 'partnership-in-care' refers to paediatric care in which parents and nurses work together (Shields, 2015). This kind of approach goes against the traditional 'medical model' of health care, in which patients and their families are reassured rather than treated as decision-makers. However, some individuals and their families prefer a more participatory approach to a paternalistic one (Chattu and Kumar, 2018).

A further term that can be discussed concerning FCC is Child-Centered Care (CCC), which means that children and their interests must be at the center of healthcare workers' thinking and practice (Carter and Ford, 2013). CCC also refers to enabling children and young people to be active participants in their care. It can be considered a further development in the ongoing evolution of FCC or as an extension of this approach. It should be noted that in FCC and CCC, a child's health and social well-being cannot be the sole focus; both must be taken into account (Lee, 2015).

According to Franck and Callery (2004), the difference between FCC and CCC is one of emphasis and reflects the extent to which children's concerns are reflected in the organization of care. CCC recognizes children as self-aware social actors in and of themselves. Its underlying assumption is that children's views are not always the same as those of their parents or healthcare providers, and that, when given the opportunity, children can represent themselves. Because professionals may assume that there is a shared family interest, the term FCC can mean that the child's voice is subsumed under that of the family as a whole (Lee, 2015). When this is not the case, such as when the child has a different perspective from the parents or in cases of child neglect or abuse, the FCC approach may face difficulties.

Richards et al. (2017) argued that parents might avoid participating in decisions related to their children's health care because they feel that nurses know better than them, or that nurses might be annoyed if they attempt to interfere (Shields, 2015). Parents want to avoid the embarrassment that can arise from asking a question to someone in a position of authority, who may make them feel patronized (Richards et al., 2017). This can lead to a deep-seated apprehension toward seeking help from doctors and nurses. The child's health may suffer as a result, with the possibility of delays in treatment and increased morbidity (Neill and Coyne, 2018).

The Benefits and Priorities of FCC

A child's illness, treatment, and surroundings, along with other factors such as the need to trust nurses, have all been linked to parents' high levels of stress and anxiety in paediatric critical care settings (Neill and Coyne, 2018). This stress and anxiety may affect parents' ability to comprehend information, make well-informed decisions, and perform in the manner in which they are used (Foster et al., 2016). Indeed, most people would agree that increasing parents' anxiety levels, as well as their fear of being patronized or seen as a nuisance, will reduce their ability to participate in the planning and delivery of care (Neill and Coyne, 2018; Foster et al., 2016).

In the first half of the 20th century, hospitalized children were cared for solely by medical professionals, with parents' access to their children either severely restricted or prohibited (Abdel Razeq et al., 2021). Attitudes and practices began to shift largely due to Bowlby's work in the 1950s and 1960s, and to Robertson (1958), whose research focused on behavioral changes associated with the separation of hospitalized children from their mothers. In response to these contributions, articles appeared in the nursing literature advocating not only increased visiting hours but also permitting the mother to room-in with the child (Abdel Razeq et al., 2021, Abdelkader et al., 2016).

The term FCC arose during the 1980s in the United States. Families of hospitalized children wanted to work more closely with healthcare professionals and were successful in advocating for changes that would allow them to care for their children at home and in the community (Care, 2011). US hospitals came to recognize the critical role parents and family members play in improving the care of patients who are unable to voice their concerns. As a result, they increasingly adopted the FCC approach (Bell, 2016). This involved maintaining and strengthening family roles, along with the natural bond that exists between the family and the child, in order to promote healthy family functioning even when a member of the family is sick. In a study on the effects of a mother's presence in a hospital, Fagin (1966) found that hospitalized children whose mothers are allowed to stay in the same room with them during their stay are less likely to suffer from severe emotional and behavioral problems after their release. Consequently, Fagin reached the conclusion that nurses' roles and attitudes should be adjusted to 'encourage the mother to become a participant in the hospital experience' (p. 69). In line with this recommendation, the first accomplishment of FCC was the physical presence of the family at the bedside of the patient (Neill and Coyne, 2018; Festini, 2014). In terms of the nurse's role, most experts agree that this is significant in helping families to effectively adapt to FCC, and in supporting their decision-making through displays of empathy and compassion (Abdelkader et al., 2016).

FCC aims to improve the quality of care for children by empowering caregivers with the knowledge and conviction that children are shaped by the people with whom they form relationships (Neill and Coyne, 2018). For paediatric nurses, adopting FCC serves as a framework for caring for children in a way that promotes not only physical health but also healthy emotional and psychological development (Kuo et al., 2011). Studies examining family roles and levels of involvement within health care have found that the most compelling evidence for the efficacy of FCC is in the efficient use of resources and the promotion of physical and mental well-being, with evidence for efficacy in transition and cost containment being less compelling (Neill and Coyne, 2018; Kuo et al., 2011).

Research has recently indicated that one of the main benefits of FCC is enhanced healthcare decision-making as a result of improved information and collaboration between professionals and families (Bell, 2016; Festini, 2014). Achieving this requires education and training, as well as support and tools, in order to ensure that all staff and healthcare professionals have a shared understanding of FCC practices. Several different healthcare service providers in a single geographical area could participate in this training in order to improve the level of collaboration between them (Abuqamar et al., 2016; Festini, 2014).

Family members and close friends often both provide and coordinate care. This involvement can improve outcomes for children needing medical and supportive services (Nursing and Midwifery Council [NMC], 2018). For example, recent research shows that family caregivers can help explain to children the comments and instructions made by clinicians during medical visits, and they can also communicate information about children's health and well-being to health and social care professionals (Bell, 2016).

PREVIOUS STUDIES

Clay and Parsh (2016) argued that hospitals are being transformed by FCC, in a way that improves patient outcomes and increases staff satisfaction while lowering costs. Although each hospital develops a set of FCC principles unique to their organization, most hospitals share the same core values in that they respect the role of family members in the healthcare experience of their patients. They build relationships with patients and their families and help them understand how their strengths and weaknesses can impact care (Neill and Coyne, 2018; Clay and Parsh, 2016). Patients are more likely to participate in treatment when their needs are given top priority, and treatments are more effective as a result (Hill et al., 2018; Clay and Parsh, 2016).

It is generally believed that in hospitals where FCC is part of the corporate culture, this approach helps to improve patients' health outcomes, as well as the satisfaction of patients, families, and employees (Neill and Coyne, 2018). Indeed, faster recovery, reduced use of healthcare resources, and fewer visits to A&E are all associated with the use of the FCC (NMC, 2018; Bell, 2016).

In recent decades, satisfaction has increasingly been used to evaluate the quality of care and the meeting of parents' needs and expectations in PICU settings (Abdelkader et al., 2016). Patients' overall satisfaction with their hospital stay can be increased by improving communication and the care environment's facilities (Clay and Parsh, 2016). In terms of the satisfaction of parents and children, this can be increased if the physical environment of the

hospital is clean and quiet (NMC, 2018; Bell, 2016). Furthermore, patient satisfaction will rise if hospital buildings are decorated with vibrant colors and greenery (Hill et al., 2018).

Another way to improve patient satisfaction in PICU settings is to ensure effective communication between healthcare providers and parents (Vasli et al., 2015). This occurs when nurses actively listen to the preferences of the family as regards to the child's care plan, showing empathy and respecting their wishes. There is a strong correlation between parent satisfaction and the success of the planning process. However, it is not uncommon for nurse practitioners to be unaware of the specific needs of patients and their families, especially when it comes to sick children (Sundal and Vatne, 2020).

During consultations and hospitalizations, sick children's families increasingly share networks with multidisciplinary teams. Some of these teams may include geneticists as well as experts in advanced nursing practice (Foster et al., 2016). In critical care units, communication between team members, parents, and patients has become more difficult due to the increasing number of participants, the complexity of care required by paediatric patients, in addition to the rising use of technology to facilitate communication (Sundal and Vatne, 2020).

Communication has not always been seen as a priority in healthcare settings, particularly before the launch in 2006 of the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey. In this survey, a hospital's overall satisfaction score can be accounted for by 25 percent of communication (Hill et al., 2018). Notably, the Children's Health Insurance Program and the Centres for Medicare & Medicaid Services (CMS) have begun requiring paediatric hospitals to administer an HCAHPS for young people. (Neill and Coyne, 2018).

According to van Mol, et al. (2018), the quality of care received by children in the PICU is significantly influenced by communication with and involvement from the families (Hill et al., 2018). Individual adjustment to illness or disability may be facilitated or hindered by family dynamics. Parents and caregivers of children must be flexible in their roles, communicate effectively, manage their emotions, and work together as a team to meet the treatment demands, demonstrating the impact of family functioning and its role as an indicator of individual adaptation (Vasli et al., 2015).

FCC has still not been fully applied around the world, even though it is a recommended approach to caring for children. In a study of an Iranian children's ward, Vasli et al. (2015) found that a 'non-possessed environment' and 'environment is not fit for children' were two indicators that paternalism was pervasive in the ward. The first thing that the researchers noticed was that the environment of the ward had not been designed with children in mind, and as a result, neither the child nor their family felt comfortable or at home. The ward was identical to an adult one except for the color of the walls (pink) and the pattern on the curtains (flowers) (Hill et al., 2018; Vasli et al., 2015).

The researchers in this study found that toys, a mattress, pillows, and clothing were among the items that parents were unable to bring to the hospital. Moreover, all of the patient's belongings, including their clothing, were given to their parents upon admission (Sundal and Vatne, 2020;

Vasli et al., 2015). When one of the supervisors was interviewed, she was enthusiastic about the idea of providing children with access to their belongings (Abdelkader et al., 2016; Vasli et al., 2015). The problem was that there were strict rules prohibiting the entry of anything from outside the hospital into the ward. Vasli et al. (2015) were critical of this restrictive approach and suggested that children should be allowed to have their toys, clothes, and pillows with them on the ward.

Western countries appear to have effectively adopted FCC, although there are doubts about how this can be determined. Smith and Coleman (2016) claim that FCC is more a nursing method than a nursing theory, suggesting that its application should be relatively easy to observe. However, of the many studies on FCC's effectiveness, none have successfully shown that nurses actually use it or that it has any discernible impact on the care of hospitalized children (Sundal and Vatne, 2020; Valizadeh et al., 2017).

The case of a young Middle Eastern girl – referred to here by the pseudonym Lela in order to protect her identity (NMC, 2015) – serves as an example of FCC in action and of the obstacles it may face. Lela was diagnosed with tufting enteropathy, a rare congenital disease that causes severe diarrhea and an inability to absorb nutrients. One week after Lela's mother was discharged from the hospital, having successfully given birth to Lela, she attended A&E and reported that her daughter had nonstop diarrhea. On admission, Lela was lethargic; she had an increased heart rate of 215 beats per minute; and she was suffering from severe dehydration. The family believed that the child had a viral infection, as is common with newborns.

A multidisciplinary meeting was scheduled with an emphasis on transparency and honesty with the family (Foster et al., 2016). The team responsible for Lela's care informed the family that Lela had an inherited genetic disease and discussed the treatment plan, including the use of total parenteral nutrition (TPN), which is a special nutritional formula. The team outlined the benefits of this treatment and the risks if not implemented, above all that Lela might die from dehydration (Carter et al., 2014). As she had persistent and watery diarrhea, she was also likely to face difficulties gaining weight.

Providing the family with comprehensive and objective information on a regular basis is one of the FCC principles that was followed in Lela's case. The nurses and the parents had a conversation based on compassion and empathy. Riess (2017) asserts that a lack of compassion and empathy from a healthcare provider can have a negative impact on a patient's willingness to adhere to their treatment plan. This is because patients may have a lower level of trust in their healthcare providers, which is likely to result in worse health outcomes (Riess, 2017; Pelzang, 2010).

Although Lela's treatment was discussed in detail with her family, they initially refused TPN. As a result, a referral to a social worker was suggested. Following a meeting with the social worker, the family's consent was obtained for starting the TPN, in line with ethical values and the professional code (NMC, 2018; (Hill et al., 2018). Lela was admitted to the hospital on a long-term basis due to her need to access TPN and a port-a-cath.

Another principle that was implemented in Lela's case is facilitating collaboration between parents and healthcare professionals at all levels (NMC, 2018). After Lela was hospitalized for

life-threatening dehydration, her mother stayed with her while she was admitted to the ward. From the beginning of her admission to the PICU, her mother actively participated in her care. She learned how to access the port-a-cath line and assess it for infection. Additionally, with the nurses' support, she was able to administer the TPN formula to her daughter. The nurses assessed her collaboration and applied it as part of Lela's care plan. Lela was happy and comfortable with her mother providing care, and this helped her condition to remain stable. As argued in a study by Carter et al. (2014), parental attendance and participation during the care of sick children results in better outcomes and increased levels of satisfaction (Erker et al., 2018).

Lela's father worked for a private oil company, and so was often away from home. He had to travel to foreign countries and attended many conferences and courses. The company that he worked for owned a hospital, which is where Lela received care. One of the company's policies was that whoever works for them has the right to refuse any person from visiting their child in the hospital, even if the person is the child's other parent. During Lela's long-term hospital admission, her father's relationship with her mother deteriorated and eventually, they got divorced. Lela's father subsequently asked the hospital to prevent her mother from visiting Lela in the hospital, despite her involvement in the child's care.

When Lela's mother stopped visiting, Lela began to experience psychological problems, and this had an impact on her health condition. A psychiatrist was invited to meet with her and discuss her feelings. Lela was in despair; she felt abandoned and believed that she was responsible for her parents' divorce. This shows how, in several key respects, Lela's care ultimately failed to follow the principles of FCC. Adopting the approach should, in theory, allow the family to be a constant presence in a sick child's life (Hill et al., 2018). However, in some Middle Eastern countries, the father automatically gains custody of a child in the event of a divorce from the mother. This is a result of cultural factors, notably the influence of Islam and Sharia law (Sundal and Vatne, 2020). As shown by Lela's case, a possible outcome is that the father stops the mother from participating in the child's health care.

The second failure, in this case, is one of policy. The hospital and the multidisciplinary team failed in writing a policy that guaranteed the child's right to see the mother. However, no action was taken in the Lela case. This can be seen to have violated the United Nations Convention on the Rights of the Child, which states: 'No child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence, nor unlawful attacks on his or her honor and reputation' (Lundy et al., 2013).

(Farokhzadian et al., 2021) argue that there remain several factors standing in the way of applying FCC in Middle Eastern countries. These include the more formal responsibilities of ward nurses (e.g., writing nursing reports) and the lack of training for nurses in FCC programs. Most importantly, health institutions in Middle Eastern countries tend to follow the paternalistic approach to care, which does not give priority to the preferences of children and their families (Farokhzadian et al., 2021). However, it should be noted that Farokhzadian et al.'s (2021) study only compared barriers to FCC in one hospital in Iran. Moreover, aside from mothers and nurses, no one else involved in the paediatric care process was taken into consideration (Farokhzadian et al., 2021).

As a contribution to the debate about FCC practice in Middle Eastern countries, the following recommendations are proposed. First, nurses and other healthcare workers should recognize that it is beneficial to show a positive attitude toward patients' families and to understand that they are the foundation of patient care under FCC (Sundal and Vatne, 2020). Second, as part of this approach, nurses should spend adequate time with parents and serve as a resource for their education, giving them the tools, they need to care for their children while they are in the hospital (Carter et al., 2014). Third, in order to provide a suitable care environment and transform paediatric departments, it is necessary to take into account the perspective group age in providing the care for instance, young children like painting and colorful walls, but teens prefer games and board games. They don't care if the wall is painted or not. (Hill et al., 2018, Farokhzadian et al., 2021).

Fourth, healthcare professionals, including nurses can reduce the barriers to FCC by gaining a better understanding of the circumstances in which these barriers arise, especially during the admission and discharge process (Farokhzadian et al., 2021, Jolley and Shields, 2009). To this end, educational hospital administrators need to look into these issues that contribute to FCC barriers at both the national and regional levels (Farokhzadian et al., 2021). They should also focus on reducing these barriers so that nurses and patients' families can collaborate in providing appropriate care for hospitalized children.

Lastly, children's parents are a valuable part of the healthcare team and should be viewed as a valuable resource for reducing FCC barriers during the hospital stays of their children (Sundal and Vatne, 2020). Therefore, it is essential to work with parents to identify the special considerations of a child and involve them in providing care for their child when they are at a medical facility (Carter et al., 2014). In many cases, mothers are the ones who are directly involved in their children's hospital care. Consequently, they often have a better understanding of the obstacles to FCC delivery than other members of the family.

CONCLUSION

The use of FCC in paediatric care is widely supported and applied (Jolley & Shields, 2009). Under this approach, during a hospital stay, healthcare professionals consider the needs of the patient's family as well as the needs of the children. (Coyne et al., 2011). Respect and dignity, information sharing, participation in care and decision-making, and collaboration between patients, families, and the healthcare team are the aims of FCC (Hill et al., 2018; Dennis, et al., 2017). These aims are underpinned by the belief that families should be involved in healthcare decisions and empowered in providing care. While FCC is followed in many parts of the world, there remain barriers to implementing it in Middle Eastern countries. This is unfortunate because, as suggested by the case study discussed in this paper, the application of FCC in paediatric care can lead to better outcomes for children.

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