

**Children's and Parents' Experiences and Expectations of their
Roles in Hospital During the COVID-19 Pandemic – A
Constructivist Grounded Theory study**

Volume 1

**A thesis presented to Trinity College Dublin for the degree of
Doctor of Philosophy**

2023

By

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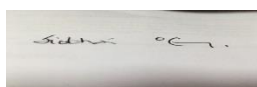
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Declaration

I declare that this thesis is entirely my own work. It has not been submitted in any form as an exercise for a degree or award at any other university.

Information derived from the published or unpublished work within this thesis has been acknowledged in the text and a list of references is given.

Signature:



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Date:

06/09/2023

Permission

Acknowledgement

I would like to thank the following people without whom I would not have been able to complete this thesis.

Firstly, I would like to acknowledge the people who supported me in the School of Nursing and Midwifery at Trinity College Dublin, specifically Marie-Pierre Lavergne who supported me and answered my queries always in a timely and professional manner. To my fellow PhD colleagues, thank you for your practical support and encouragement, either at our monthly Research Support and Education Days or our WhatsApp group.

I sincerely wish to acknowledge the support, expert advice and knowledge of my supervisors Professor Imelda Coyne and Professor Maria Brenner. You were always so generous with your time as you guided me through my PhD journey, always consistent, professional, supportive and positive. You taught me about academic rigour and supported me through this journey, while the COVID-19 pandemic descended on the world. You professionally and carefully balanced expected academic standards with compassion and pragmatism to ensure I got this thesis across the line. You engaged virtually with me on Zoom and continued to respond to emails as if nothing was happening. Thank you for your reliable leadership, professionalism and advice which helped to keep me focused, when we were in the grips of a global pandemic and repeated lockdowns.

To the Clinical Nurse Managers/Clinical Nurse Education Facilitators who were also the gatekeepers, you always greeted me as a member of the team on your clinical areas and suggested children and parents to participate in my study, despite your commitment to clinical practice. I would like to thank Ben Meehan from QDATraining who supported me when I was challenged with the functions of NVivo, your prompt responses and helpful advice was always spot on.

To the fabulous children, adolescents and their parents who agreed to participate in this study, I will be forever grateful to you all for giving so generously of your time and sharing your views with me to improve the experience for future hospitalised children/ adolescents and their parents. I will always be in awe of your resilience and your positive attitude to being in hospital, especially during a pandemic.

To my friends especially Fiona and Rosie who stood by me when I missed special occasions and included me in all the messages to keep me included in all the happenings that I was actually missing, but virtually included in.

To my siblings Mary, Michéal, Bríd and Sheelagh for your understanding and support when the heat was on, and not having any huge expectations of me for the last few months while I was knee deep in this thesis. A special word for Sheelagh, James and Emer who helped to keep me grounded and in contact with the world while I was completing this thesis. Our late parents, Alice and Tom, were our driving force and inspiration in our early lives and continue to keep us linked to each other and to them. Mom was a dedicated education enthusiast, a nurse, a midwife and a teacher, she would just love to be around to read this thesis.

Finally I want to dedicate this thesis to my beloved husband Brendan who kept the dinner on the table (literally!) and our wonderful daughter Ciara who suffered the cross of not having me as freely available to her as a Mom should be to her daughter, I'm looking forward to changing all that.

This PhD study was generously funded by a Fellowship grant awarded by the National Children's Hospital Foundation, with additional funding by Children's Health Ireland.

Abstract

Background

Family-centred care (FCC) is the preferred model of care for hospitalised children and their families, both in Ireland (Coyne, 2013) and internationally (Feeg *et al*, 2016). There is no internationally agreed definition for FCC for hospitalised children. This lack of definition has been cited as contributing to an inconsistent application of FCC in practice (Coyne *et al*, 2011; Feeg *et al*, 2016; Coats *et al*, 2018).

A concept analysis identified that increased day-case activity, early discharge and increased patient throughput results in reduced time spent in hospital and increased patient acuity. An extensive literature review revealed that parents wish to participate in the care of their child in hospital, but the degree to which they wish to do so varies and must be negotiated between the nurse and the individual child and parent (Coyne, 2013; Watts *et al*, 2014; Feeg *et al*, 2016). There is also evidence that children's nurses have been applying some elements of FCC to their practice for decades, albeit inconsistently. The evidence indicates that children's nurses have been applying some elements of FCC to their practice for decades, albeit inconsistently. There is no hard evidence to inform healthcare professionals if the application of a family-centred approach to care makes a difference to the families' healthcare experience. Furthermore the voice of the child is noticeably absent from existing research on the topic.

Aim

To explore children's and parents' experiences and expectations of their roles while in hospital and develop a theory to explain the involvement of the child and parent in care in hospital.

Methodology

This research study used a constructivist grounded theory approach (Charmaz, 2006; 2014). Ethical approval was obtained. Data were collected during the Coronavirus 2019 (COVID-19) pandemic, through semi-structured, face-to-face interviews with hospitalised children (n=9) aged 9-12 years and with adolescents (n=14) aged 13-16 years. Parents (n=24) of hospitalised children were also interviewed. Initially purposeful sampling was used. Data collection and analysis occurred simultaneously. Following analysis of the data from initial interviews, theoretical sampling was employed until data saturation was achieved.

Findings

The three main concerns of children and adolescents were: a) my parent keeping me company and providing emotional support, b) my parent helping me/advocating for me and c) doing my own personal care. The parents' key concerns were a) keeping my child company, b) advocating for my child, c) parental roles evolving with limited guidance from nurses, d) parents helping nurses and e) parents "making do with" inadequate facilities. The emergent grounded theory that explains the parents' roles and responsibilities while being with their sick child in hospital during the COVID-19 pandemic is: "An advocating companion with parental roles evolving in an *ad hoc* manner".

Conclusion

Ongoing education for registered nurses must include child- and family-centred care and advocacy. Parents helping nurses in the context of the nurses being constantly busy was a recurring concern of parents. Parents clearly need better support, and clear negotiation of care. The development of the role of the Healthcare Assistant may be another way of supporting nurses in the delivery of safe and effective child- and family-centred care.

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Chapter 1

Introduction and Background to the Study

*“Parents should be allowed to visit whenever they can, and to help
as much as possible with the care of the child.”*

(The Platt Report, Ministry of Health, 1959: p. 38)

1.1 Introduction

The way in which children's healthcare is planned and delivered has changed significantly over the past 60 years. There is evidence that nurses, and healthcare professionals working in children's services, consider that a family-centred approach should underpin the delivery of care and services for children and their families (Coyne, 2013; Feeg *et al.*, 2016). This chapter will provide background by discussing the evolution of family-centred care (FCC) in the context of children's nursing internationally. This will provide a context for this research and help to begin to understand the delivery of FCC in practice. It is also important to understand the historical perspective of FCC, to begin to understand how it has come to be held in such high esteem among all healthcare professionals working with children, and specifically among children's nurses. Current practice in children's healthcare in Ireland will also be outlined in order to contextualise this study. Finally the ambiguity that exists surrounding the understanding of the concept among children's nurses will be discussed.

1.2 The evolution of family-centred care

During the 1700s, hospitals were established to care for ill people whose impoverished families were unable to care for them at home, due to lack of space, knowledge and/or money. Sick children, whose families could afford to care for them at home, were not admitted to hospital. During this time the modern hospital began to appear, including Westminster Hospital in 1719 and Guy's Hospital in 1724, both in London, and in 1751 the first hospital in the United States of America (USA) opened its doors in Pennsylvania (Starr, 1982). While these hospitals served the medical needs of sick people, only the poor and destitute attended. When someone became ill from a family of the middle or upper classes, their families, who were considered responsible and educated, cared for them at home, with the help of neighbours (Giganti, 1998). Hospitals at this time were staffed with trained doctors, however nursing staff were untrained workers. None of these institutions cared specifically for children, children were cared for at home or, if they needed to be admitted to hospital, they were admitted to general wards and cared for with adults.

1.2.1 The establishment of children's hospitals

The first children's hospital was established in 1802 in Paris (Jolley and Shields, 2009), followed by the establishment of the National Children's Hospital in Dublin in 1821, Great Ormond Street Children's Hospital in London in 1853, the Royal Manchester Children's Hospital in 1855 and the Royal Hospital for Sick Children in Glasgow in 1883 (Davies, 2010; Shields, 2011). In Australia, Sydney Children's Hospital was established in 1852, while in the USA the Children's Hospital of Philadelphia was established in 1855. These hospitals were established to provide a service to children of impoverished families (Giganti, 1998; Davies, 2010). Although industrialisation had begun, poverty and ill health continued to

prevail during the late 1800s and early 1900s in the Western world. Hospitalised patients, both adults and children, came mainly from poor families, their life expectancy was low, and standards of care in hospitals was poor. Indeed, hospitals were places where the sick were removed from society and waited for death, since medicine was more likely to do harm than good (Davies, 2010). Pain management and infection control were poorly recognised, understood and managed due to a lack of medical knowledge and effective medication (Valentinuzzi, 2009). Slowly during this time new knowledge and technology became available as a result of basic clinical research, and hospitals became centres of recovery and rehabilitation (Valentinuzzi, 2009). The emphasis at the time was on keeping these children away from outside influences because of the fear that visitors, such as family members, neighbours and friends, could bring infection into the hospital causing an outbreak within the hospital, hence visiting was very limited. These early children's hospitals focused on short-term care and treating mild illnesses. There was a fear that treating serious illnesses in children's hospitals could result in the disease spreading throughout the hospital which would threaten the lives of other patients. An outbreak of infection in a children's hospital could result in more lives lost than lives saved (Davies, 2010).

During these early years when children's hospitals were a new phenomenon, children were admitted to hospital without their parents. Visiting by parents was either forbidden or restricted to once or twice weekly visits for less than one hour, and these restrictions were strictly enforced (Jolley and Shields, 2009). Hospital routines were designed around the needs of the medical and nursing staff and took no account for the needs of the children whom they cared for (Shields and Nixon, 1998). Jolley (2003) in a study of the social history of children's nursing during the period 1920-1970, found that children's nursing was a regimented discipline, closely aligned to medicine, where nurses appeared to lack affection and failed to address the social and psychological needs of the child and family. Parental participation in care was not permitted, indeed parents were excluded from caring for their sick child when in hospital. Visitors, including parents, were considered a source of infection, which could be potentially life-threatening, since microbiology was still a developing science and antibiotics were at a very early stage of development (Davies, 2010). Strict visiting rules remained in place due to an emphasis on prevention of infection. While the physical needs of children in hospital were addressed, their emotional and psychological needs were ignored. As a result of restricted visiting, children in hospital were deprived of their parents' love and affection. Throughout the 1800s and into the mid-1900s hospital care of children in both Europe and the USA was dominated by unfriendly nursing and medical staff, where parents and family were only allowed limited visiting and were excluded from participating in the care of their child (Davies, 2010). Nurses and doctors at that time believed that the presence of parents was emotionally upsetting for the child, and

maintained that it was in the best interests of the child if the parents did not visit (Alsop-Shields and Mohay, 2001). There is evidence that such restrictions continued to remain in place into the early and mid-1900s in Canada, the USA (Institute for Family Centered Care, 2013), the United Kingdom (UK), Ireland, Australia and New Zealand (Alsop-Shields and Mohay, 2001; Davies, 2010).

1.2.2 Attachment theory and maternal separation

During the 1930s and 1940s John Bowlby, a psychologist and child psychiatrist working at the Child Guidance Clinic in Tavistock, London, believed strongly that children's early childhood experiences were closely related to subsequent emotional problems in later childhood and adolescence (Alsop-Shields and Mohay, 2001). Bowlby's research identified a relationship between juvenile criminals and traumatic separation from their mother at an early age (Bowlby, 1944). Bowlby and his research team examined intensively the lives of 44 children who had been brought to the clinic following episodes of stealing. The histories and behaviours of the "thieves" were compared with 44 other children who were attending the clinic for other reasons. These other children were selected because they "did not steal and whose age and intelligence fell between the upper and lower limits of the delinquents" (Bowlby, 1944; p. 21). These children were considered the control group. Fourteen (32%) of the thieves had "affectionless characters", meaning they did not exhibit normal affection, shame or take any responsibility for their actions. None of the control group were described in this way. Twelve (86%) of the 14 "affectionless" children had been separated for long periods, of six months or more, from their mothers, or mother figures, before their fifth birthday. Most of these separations were due to hospitalisation (Bowlby, 1944). There were no "affectionless" children identified in the control group. Bowlby (1944) concluded that these children were "affectionless" because of prolonged maternal separation in their early years. During these prolonged hospital admissions these "affectionless" children lacked the love needed for normal personality development, which contributed to them becoming thieves or what he called juvenile delinquents. As a result of his findings, Bowlby (1944) claimed that avoiding prolonged separation from a child's mother before the age of five years could prevent the development of such "affectionless" personalities, calling for further research to include how psychological and socio-economic factors might explain the problem further. Bowlby's subsequent research on attachment relationships and separation of children from their primary carer, most often their mother or mother figure, recognised that young children become anxious and clung to their mother or mother figure if separated from her for any length of time, especially in the face of a perceived threat. This reaction of the child to maternal deprivation suggests that damage to this relationship during the child's early years might result in adverse effects on character development and personality disorders which may persist throughout life (Bowlby, 1953). Hence separation anxiety and attachment theory were born. When a child is separated from their primary carer for an

extended period of time, it was likely to lead to the child experiencing long-term psychological problems (Alsop-Shields and Mohay, 2001).

1.2.3 The effects of hospitalisation on young children

James Robertson, a social worker who worked with Bowlby in London, and his wife Joyce, noted changes in their young daughter's behaviour after she had been hospitalised for a tonsillectomy as a four-year-old. They ascribed these behavioural changes to the distress she suffered while in hospital (Shields, 2011). Consequently James Robertson focused his research on attachment theory on the effects of hospitalisation on young children. He carried out observational research by means of film in 1952 "*A Two-year-old Goes to Hospital*". The film recorded the main events that occurred during a two-year-old child's eight-day stay in hospital for an umbilical hernia repair, including the admission procedure, daily samples of the child's nursing care and parental visits. Early in the recording the child is crying and pleading bitterly for her mother. When her pleas are not answered and her mother fails to return, the child is seen to gradually become subdued and withdrawn. She stops crying and calling out for her mother, and appears to be settled. However, to the more discerning observer it is clear the child is not fine, but rather, in the absence of her mother returning, has given up protesting, has given in to despair and is miserable. The purpose of this experiment was to collect and present data on child behaviour in a stressful situation, undistorted by the interpretation of an observer. Robertson (1952) argued that any prejudices he might have had did not influence the recording in any way. The viewer could make his/her own interpretations of what was captured on film. This film captured the behaviours that hospitalised children exhibited when separated from their parents and became a standard teaching tool in many nursing and medical schools throughout the world (Robertson, 1958a). In further research by Robertson and his wife, they recognised that children separated from their parents while in hospital suffered distress and identified three stages of a child's response to separation during a hospital admission as protest, despair and denial (Robertson, 1958b). Protest was often misinterpreted by the nurses and doctors as bad behaviour, despair as the child settling into life in the hospital ward when in fact the child was actually displaying signs of hopelessness, while the third stage, denial, was described as the child developing detachment which Robertson (1958a; 1958b) claimed may result in the child being anxious, insecure and rejecting his mother when he returned home. Robertson and his wife presented their work and the work of Bowlby to healthcare staff throughout the country and are credited with bringing Bowlby's work to the attention of politicians, healthcare staff and the general public. Robertson continued to promote better care for children in hospital throughout the 1950s and 1960s (van der Horst and van der Veer, 2009). Robertson made another documentary film in 1958 "*Going to Hospital with Mother*" to demonstrate the positive difference that occurs when a mother is admitted to the hospital with a child (Robertson, 1958c). This second film was a study of the relationships

between a mother and child in hospital, and between a mother and the hospital staff. Robertson (1958b; p. 382) claimed it showed “the serenity of the situation that is created, even when children are very ill”. He concludes that the mother's presence with her sick child in hospital avoids maternal separation and “helps to prevent anxieties arising from illness, pain, investigation and operation from becoming cumulatively overwhelming” (Robertson, 1958b; p. 382). During this time there is some evidence in the literature that practices were beginning to change in some hospitals in the UK and Australia, where more flexible visiting arrangements for parents were being introduced with many advantages noted. Such advantages included the children being less anxious, less distressed and less lonely when their parent (usually their mother) was with them in hospital (van der Horst and van der Veer, 2009).

Despite all this evidence and a request from the Minister of Health in the UK to introduce daily visiting for parents of sick children in hospital, there was persistent reluctance by hospital staff to do so. This was thought to be due to a fear on the part of the nurses and doctors that parental presence may interfere with their established working patterns, hospitals were controlled primarily by the medical consultants and matrons (Davies, 2010). It was also argued that special purpose-built wards were needed to accommodate mothers with their sick child in hospital (Robertson, 1958a). The risk of infection was also still present and very real. The work of Bowlby and Robertson is considered to be the beginnings of FCC in child healthcare practices. However, Bowlby's and Robertson's research has been criticised for over-simplifying existing theories and for making broad assumptions using minimal datasets (Alsop-Shields and Mohay, 2001). Nonetheless their legacy of the awareness of attachment and maternal separation at an early age continues to influence research and policy in child development, child psychiatry and in children's nursing internationally. Although their works may not be considered objective, valid or reliable by today's research practice standards, they have survived the test of time and are considered the research which underpin the philosophy of children's nursing to this day.

1.2.4 The Platt report

As a result of the work of Robertson and Bowlby, the Ministry for Health in the UK established a committee of parliament in 1956 whose remit was to examine the welfare of children in hospital and make recommendations for hospital authorities. The committee was chaired by Sir Harry Platt, the then President of the Royal College of Surgeons, consequently their report became commonly known as the Platt Report (Ministry of Health, 1959). The committee included one Registered Sick Children's Nurse (RSCN), and they met 20 times during three years and made 55 key recommendations. The publication of the Platt Report in 1959 contained far-reaching recommendations on how children should be cared for in hospital and heralded a revolution in children's healthcare worldwide. It is

still referred to today as the cornerstone of improvements in the care of hospitalised children (Priddis and Shields, 2011). A number of radical and influential recommendations emanated from this report, such as giving consideration to the admission of mothers with their child, especially for children under five years of age, that accommodation be provided for the mother, that school/play facilities be provided for children in hospital, that the Nurse-in-Charge should hold a RSCN qualification and that educational up-dates for ward sisters should include the emotional needs of the child. The most significant recommendation relevant to this study was that there should be unrestricted visiting for parents of sick children while in hospital, regardless of the age of the child, and that the parent should be allowed to be resident and help as much as possible with their child's care while in hospital (Ministry for Health, 1959).

Around the same time similar work was being carried out in the USA. A committee was established in New York City in 1955 to examine the effects of hospitalisation on children and recommended that parents be allowed unlimited visiting when their child is in hospital (Shields and Nixon, 1998).

1.2.5 The post-Platt report period

Despite the recommendations of the Platt Report, there is evidence in the literature that both the nursing and medical professions internationally continued to resist parental involvement in care throughout the 1960s and 1970s (Shields and Nixon, 1998; Alsop-Shields and Mohay, 2001; Jolley, 2003; Davies, 2010). During this time parents were not generally accepted onto children's wards. A culture of paternalism existed in Western societies, where the healthcare professional was held in high esteem because of his/her educational attainment. A paternalistic doctor-patient relationship prevailed, where the patient played a passive, compliant role, expected to co-operate with the doctor (Brody, 1980). In the children's healthcare setting there was a belief that the "expert" was the doctor or nurse, and an expectation that when he/she told the parents what to do, the parents would comply without questioning (Wells, 2011). Children's wards were cold and controlled environments; prevention of cross infection was all-important, there was no evidence of play or fun, tidiness and discipline took priority over the emotional needs of the child or the parents (Shields and Nixon, 1998; Jolley and Shields, 2009).

1.2.6 The growth of advocacy groups

In the 1970s and 1980s child and family advocates began to voice concerns about restricted visiting and the lack of psychosocial support for children in hospital. They exerted pressure on politicians, healthcare professionals and hospital managers to implement the recommendations of the Platt Report, specifically to provide accommodation for parents so that they could stay with their child in hospital and to implement unrestricted visiting for

parents (Davies, 2010). In 1982 a survey of all children's wards in England identified a wide variation in visiting times for parents (Thornes, 1983). Of the wards surveyed 89% provided some form of overnight accommodation for parents. However, some units still provided no accommodation whatsoever, suggesting that parents in these hospitals were afforded no opportunity to stay with their sick child. There continued to be strong opposition to the recommendations of the Platt Report within the healthcare professional community, but the growth of advocacy groups continued. Groups such as Mother Care of Children in Hospital in the UK now known as Action for Sick Children and the Association for the Care of Children in Hospital (ACCH) in the USA were instrumental in advocating for child health services and the development of FCC (Jolley and Shields, 2009).

Advocacy groups helped to promote the need for family involvement with hospitalised children in the Western world. Closer to home in 1969, a survey report of 17 hospitals in Dublin where children were treated, was published by the *Organisation Mondiale pour l'Education Prescolaire* and identified visiting arrangements, accommodation for parents, education and play facilities for children as important issues which needed to be addressed. It also found that accommodation for mothers to stay overnight with their sick child was not provided in any of the 17 hospitals surveyed (Bannon, 2002). The National Association for the Welfare of Children in Hospital (NAWCH) Ireland was established in 1970 by a group of parents of sick children who began lobbying for the rights of hospitalised children (Bannon, 2002). The NAWCH is now known as Children in Hospital Ireland and continues to work constructively with all health professionals and policy makers to increase awareness of the special needs of hospitalised children (<https://childreninhospital.ie/history/>). The Association for the Welfare of Children in Hospital (AWCH) was established in Australia in 1973 (Alsop-Shields and Mohay, 2001).

NAWCH Ireland published a Charter for Children in Hospital in 1973, and in 1988 it signed up to the European Charter for Children in Hospital (EACH), which represented a significant move towards implementation of recommendations of the Platt Report and the principles of FCC. The Charter helped to promote the need for family involvement in care of the hospitalised child and the need for parent accommodation. Article two of the EACH Charter states:

“Children in hospital shall have the right to have their parents or parent substitute with them at all times.” (Article 2) Association for the Welfare of Children in Hospital Ireland). (<https://childreninhospital.ie/>).

Article three goes on to state that accommodation should be offered to parents and that they should be encouraged to stay with their sick child in hospital and supported to actively participate in their child's care.

During the late 1970s parent accommodation became available in the three children's hospitals in Dublin. Despite this, the uptake of parents staying with their sick child in hospital was poor (personal communication 26th July 2018 with Ms Maura Connolly, former Matron of the National Children's Hospital, Dublin). In fact parental presence with their child in hospital remained low until much later, with Dingeman *et al* (2007) reporting that parents staying in hospital with their sick child increased from less than 50% in the early 1990s to more than 80% a decade later. While healthcare professionals in the 1970s and 1980s were aware of the psychological effects on children of hospitalisation and separation from parents, the general public, i.e. the parents, may not have been. A lack of awareness of the adverse effects of separation of the young child from his/her parents is a possible explanation for the low numbers of parents, exclusively mothers, who resided with their sick child in hospital at this time. Another possible explanation was the structure of the family in Ireland at that time. According to the 1981 census report (Central Statistics Office, 1981) 24% of households were made up of the father, who was generally the sole earner, mother and three children under the age of 14 years of age, while a further 22% had more than four children in the household. It may have been difficult for the mother to leave the family at home alone and unsupervised while the father was out at work. According to Alsop-Shields and Mohay (2001) such reforms were opposed by some people, including professionals, who believed the mother's place was in the home, providing for her husband and family, while the sick child was cared for in hospital by nurses and considered safe.

1.2.7 Parental involvement in care

Around this time children's hospitals in the developed world were gradually moving towards inclusion of parents in the nursing care of their sick child (Wood, 2008). Casey (1988) described children's nursing as a partnership with the child and family. This partnership approach to children's nursing is recognised as a precursor to FCC as we know it today (Coyne, 1996). Finally, it seemed, the nursing and medical professions were taking on board the recommendations of the Platt Report (Ministry for Health, 1959), and parental presence on children's wards was becoming commonplace. Casey's (1988) partnership model of care proposes that the process of nursing is carried out in partnership with the child and family, with the nurse explaining how the partnership works; and together with the nurse, the child and the family decide to what extent, if any, they would like to participate in care. Casey (1988) asserts that parents can be educated and supported to gradually become involved in care, even in the intensive care setting. The partnership model of care recognises that the family may not always be present, and contends that nurses carry out parental care in their absence.

Coyne (1995) explored the concept of parental participation in care, and recognised the complex and holistic nature of the parent-nurse relationship. In a qualitative study of 18

parents (16 mothers and two fathers) Coyne (1995) sought to identify the main reasons why parents chose to participate in their child's care in hospital. She found that parents wanted to participate because they were concerned for their child's welfare and a consistency in the care they received. A lack of information, fear of hurting the child and failure to negotiate roles and responsibilities were key challenges parents encountered and which made caring for their sick child in hospital more difficult (Coyne, 1995). She concluded that further research into nurses' perspectives of parental participation was needed to clarify the nurse-parent relationship and enhance parental participation in care. In a concept analysis of parent participation Coyne (1996) identified negotiation, willingness, competence and autonomy as key attributes, and stated that the concept was poorly defined and in need of clarification. Although various terms have been used in the evolution of the concept of parent participation such as parental involvement, partnership-in-care, care-by-parent and FCC, the underlying theme remained parent participation (Coyne, 1996).

The Institute for Patient- and Family-Centered Care (IPFCC) was established in 1992 in the USA to promote the understanding and practice of patient- and family-centred care among healthcare professionals and the public (Johnson and Abraham, 2012). The IPFCC continues to have a major influence on FCC policy and development in the USA. The IPFCC has described the four core concepts of patient and FCC as dignity and respect, information sharing, participation and collaboration (Johnson and Abraham, 2012). This definition is not child or healthcare setting specific, and applies to patients of all ages, in any healthcare setting.

During the 1990s an abundance of nursing literature was published exploring the meaning of FCC, and its associated terms - parental participation and partnership in care - to parents and healthcare professionals (Brown and Richie, 1990; Gill, 1993; Nethercott, 1993; Palmer, 1993; Ahmann, 1994; Evans, 1994; Baker, 1995; Coyne, 1995; Darbyshire, 1995; Coyne, 1996; LeTourneau and Elliot, 1996; Bruce and Ritchie, 1997; Hutchfield, 1999). All these authors highlighted the family's central role in the child's life and the importance of the family to the child's healthcare journey. The American Association of Pediatrics (2003) endorsed FCC, incorporating it into their policy documents and affirming it as the standard of health care for all children and their families.

1.2.8 Family-centred care today

Despite the publication of numerous concept analyses on FCC from many developed countries over more than two decades (Nethercott, 1993; Hutchfield, 1999; Malusky, 2005; Mikkelsen and Frederiksen, 2011; Smith, 2018), there is still no agreement on a universally accepted definition of the concept as it applies to hospitalised children and their families. The core principles or elements of the concept have been described (Shields *et al*, 2006; Johnson and Abraham, 2012), and it is recognised as the preferred model of care for

hospitalised children internationally (Coyne, 1996; Chenery, 2004; Franck and Callery, 2004; Shields *et al*, 2006; Dunst and Trivette, 2009; Coyne, 2013; Feeg *et al*, 2016). The term is now used extensively in discussions pertaining to children's nursing, in both the spoken word and in the literature, yet a clear understanding among those using the term is not apparent. More recently there have been systematic reviews of qualitative (Shields *et al*, 2006; Shields *et al*, 2012a; Watts *et al*, 2014), quantitative (Shields *et al*, 2007; Shields *et al*, 2012b), and quasi-experimental (Shields and Huaqiong, 2011) studies which attempted to identify the effectiveness of FCC for hospitalised children when compared to standard models of care delivery. All of these reviews concluded that, due to a lack of robust empirical evidence, it is not possible to say with any degree of confidence, that the implementation of FCC either has benefits or otherwise for the hospitalised child, their parents, healthcare professionals or for the healthcare organisation.

1.3 Children's healthcare in Ireland

The population of Ireland is 4,761,865 persons as identified in the 2016 census, of which 1,129,184 (23.7%) are children aged 16 years and under (Government of Ireland, 2017). Census 2022 results have not yet been published, however preliminary results report an increase of 7.6% in the total population to 5,123,536 (Central Statistics Office, 2022). It is reasonable to estimate that the number of children living in Ireland has increased accordingly, by approximately 7% also, estimating the current childhood population to be approximately 1.2 million. Ireland has the highest birth rate in the European Union (13.7 per 1,000) with more than 63,000 births during 2016 (Government of Ireland, 2017). While the vast majority of our children are healthy, more than 20% of Irish children over eight years of age are overweight or obese (Bel-Serrat *et al*, 2017). Furthermore, in excess of 8% of Irish children live with a disability (Government of Ireland, 2017), while approximately one in three children with a disability are registered as having multiple disabilities (Doyle and Carew, 2018). A further 16% of children living in Ireland have a chronic health condition, such as diabetes, asthma or epilepsy, while 2% are acutely ill or have complex care needs requiring care within, and/or support co-ordinated from, the acute hospital setting (Hardiman, 2017). On average over 100,000 children in Ireland spend more than 3 nights in hospital per year, 75% of these children are under four years of age and almost all are unplanned admissions through the Emergency Department (ED) (Children in Hospital Ireland, 2017).

Currently, many hospital-based services in Dublin are accommodated in facilities which are considered no longer fit-for-purpose. Consequently children's healthcare in Ireland is undergoing major reconfiguration with the development of a new children's hospital to replace the existing three children's hospitals in the city. This re-configuration was a recommendation of a review commissioned by the Department of Health and Children in

2005 *Children's Health First: McKinsey Report* (McKinsey and Company, 2006). The purpose of this review was to advise on the strategic organisation of tertiary paediatric services for Ireland. It reviewed 15 internationally recognised hospitals in Australia, New Zealand, Canada, Scandinavia, the UK and the USA, and identified emerging international best practices and their implications for Ireland. The McKinsey Report advised the development of a single tertiary children's hospital in Dublin, ideally tri-located with an adult and maternity hospital.

Subsequently an extensive review of the acute children's health services was undertaken which resulted in the publication of the *National Model of Care for Paediatric Healthcare Services in Ireland* (Nicholson and Murphy, 2015). This publication describes how acute paediatric health services are best provided within a national context, with the new children's hospital designated as the central component of an integrated clinical network for acute paediatric healthcare in Ireland into the future. The aim of this National Model of Care for Paediatrics and Neonatology is to deliver acute paediatric services as close to home as possible, with all specialised and national services to be consolidated in the new children's hospital. Regional and local units will receive clinical support from colleagues in the new hospital. This publication has been informed by international best practice and is supported by health policy reports including the Bristol Royal Infirmary Inquiry (2001), Child Health Support Group, Scotland (2004) and Children's Health First, McKinsey Report (2006). The new children's hospital is expected to become operational in 2024.

1.3.1 Current practice in the children's hospitals in Dublin

Evidence-based models of nursing care guide critical thinking and decision-making for professional practice (Wood, 2013). Such frameworks support nurses in the assessment, planning, implementation and evaluation of care and the delivery of consistent, high quality patient care (Fawcett, 1995; McCrae, 2011). Models of nursing care were implemented within the three children's hospitals in Dublin during the 1990's by senior nursing management and nurse educators:

- Children's Health Ireland (CHI) at Crumlin adapted the Roper, Logan and Tierney (1996) Model into their nursing documentation.
- CHI at Temple Street adapted the Nottingham Model (Smith *et al*, 1995).
- CHI at Tallaght adapted a modified version of the Nottingham Model (Smith *et al*, 1995).

Each of the three hospitals applied a family-centred approach to care when implementing their chosen model in practice. At this time FCC was considered the preferred model of care within which to deliver children's nursing internationally (Franck and Callery, 2004; Shields *et al*, 2007; Coyne *et al*, 2011; Feeg *et al*, 2016). When implementing the model of care in each individual hospital evidence-based nursing care plans were developed. These

nursing care plans continue to be in use today and are subject to ongoing audit, regular review and update to incorporate emerging evidence. While the nursing care plans are reviewed and updated on an ongoing basis, the overarching model of nursing care applied in each hospital, i.e. FCC, has not been reviewed in the context of children's nursing in Ireland since the 1990s. With this in mind it is timely to review FCC as a model of nursing care within which to deliver children's nursing in the 21st century in Ireland.

1.4 A lack of clarity and consistency

Shields *et al* (2006: p. 1318) describe FCC as:

“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/young person, and in which all the family members are recognized as care recipients.”

It is commonly acknowledged that the entire family is affected when a child is in hospital (Shields *et al*, 2007). However, there is evidence that FCC is not always implemented consistently, with a lack of a clear understanding being cited as the main challenge to its consistent and effective implementation in practice (Coyne *et al*, 2011; Feed *et al*, 2016; Boztepe and Kerimoğlu Yıldız, 2017; Smith *et al*, 2017; Coats *et al*, 2018).

Despite the vast amount of published literature currently available on FCC, ambiguity persists. In the absence of an internationally accepted definition, the specific actions that are needed in order for FCC to occur are unknown (Kuo *et al*, 2012; Uniacke *et al*, 2018). The inconsistencies associated with applying FCC in practice as a result of this lack of clarity has been described in the literature for over a decade (Murphy and Fealy, 2007; Foster *et al*, 2010; Coyne *et al*, 2011; Smith *et al*, 2015; Feeg *et al*, 2016; Boztepe and Kerimoğlu Yıldız, 2017; Coats *et al*, 2018; Uniacke *et al*, 2018). These publications are reflective of practice internationally.

A review of the vision, mission and values statements of seven internationally recognised children's hospitals across the Australia, Canada, Ireland, New Zealand, the UK and the USA reveals that the concept of working in partnership with the child and family to improve health and well-being is overtly stated in only two of the seven statements, see Appendix 1. This finding could be considered an indication of how little progress has been made in delivering care in a true partnership arrangement between the family and the healthcare teams that is truly child-, parent- and family-centred.

1.5 Conclusion

Evidence based practice is at the heart of excellent nursing care and healthcare generally. It aims to use the best available evidence to support clinical decision-making and improve

outcomes for patients (Klimek Yingling, 2020). Excellent nursing care is dependent on having knowledgeable, accountable practitioners, a sound evidence base to support practice and the appropriate application of evidence to practice (McMahon, 2003). The strength of a professional group is reflected in the development of a set of clear concepts relevant to its practice in order for a profession to progress its existing scientific knowledge base (Weaver and Mitcham, 2008). The absence of a clear definition can lead to ambiguity, which can weaken one's understanding of a term, or concept, and compromise how it impacts quality of care (Weaver and Mitcham, 2008).

In order to form a clear understanding of the concept of FCC for hospitalised children and their families, a concept analysis was needed. This process entailed an extensive search of the literature and a comprehensive analysis of published national and international articles. The concept analysis helped to provide an operational definition and a context to the project, and establish the framework for the research.

1.6 Chapter summary

This chapter outlined the evolution of children's healthcare from the establishment of children's hospitals in the early 1800s in the developed world. It contextualised the development of FCC since it was first mooted by Bowlby in 1944, bringing the reader up to the present time. The current delivery of children's healthcare in Ireland and the models of care in use across the three children's hospitals in Dublin were discussed. The persistence of a lack of clarity around the meaning of FCC for the family and the healthcare professional internationally was acknowledged, and how this lack of clarity contributes to the inconsistent application of the concept in practice was identified. Chapter two will outline in detail the analysis of the concept of FCC for children and young people in the acute hospital setting.

1.7 Layout of the thesis

This thesis is structured in six chapters which are outlined briefly below.

Chapter 1: Background to the study

This chapter provides background to the evolution of children's healthcare internationally, briefly outlining the position children held in healthcare historically. The lack of clarity that exists around a definition of FCC and the consequent inconsistent application of it are identified.

Chapter 2: Concept analysis of family-centred care for hospitalised children and young people

This chapter presents a concept analysis to situate the research in the context of previously published theoretical literature related to the topic. The approach taken to analyse the

concept is outlined in detail. This is followed by a presentation of the findings and a discussion of the findings in the context of contemporary clinical practice.

Chapter 3: Literature review

This chapter presents a critical review of the empirical research specifically relating to children and adolescents in hospital. The framework followed is detailed and gaps in knowledge which require further research are identified.

Chapter 4: Research design

This chapter is presented in two parts.

The research methodology is discussed in detail in Part One, including the researcher's personal philosophical stance and the methodology chosen to answer the research problem. The evolution of grounded theory is outlined, and the applicability of a constructivist grounded theory approach (Charmaz, 2006; 2014) to explore children's, adolescents' and parents' experiences and expectations of their roles in hospital is explained.

Part Two of this chapter includes a description of the specific tools used to undertake the research. It includes a discussion on the ethical principles of research, gaining access to the research site, and the gatekeeping processes which were navigated before conducting this research. The method of sample selection, the consent process, data collection and analysis are outlined in detail. The researcher's reflexive stance in the research process is also addressed.

Chapter 5: The findings

The findings of the research are presented in this chapter. The explanatory grounded theory, which was developed from the participants' data, is presented at the beginning of the chapter to contextualise the findings as they are presented. Detail of the experiences of the children, adolescents and parents who participated in the research are presented using their words and stories to explain how the emergent codes and categories were arrived at, and to illuminate the main findings.

Chapter 6: Discussion

In this chapter the findings are discussed in the context of extant literature on the topic and how this research contributes to existing knowledge. The development of the explanatory theory grounded in the participants' data, which emerged from the study is presented.

Chapter 7: Implications/recommendations, strengths, limitations, trustworthiness and my reflexive account.

The implications for practice, education, research and policy are presented in Chapter 7. The strengths, limitations and trustworthiness of the study are considered. Finally, reflections on the researcher's journey are also presented.

Chapter 2

Family-Centred Care for Children and Young People in the Acute Hospital Setting: A Concept Analysis

“Children must not be separated from their parents against their will unless it is in their best interests (for example, if a parent is hurting or neglecting a child).”

(Article 9, United Nations Convention on the Rights of the Child, 1989)

2.1 Introduction

Family-centred care (FCC) has become a central tenet of children's nursing in the Western world over several decades since the publication of the Platt Report in 1959 (Ministry of Health, 1959). While it is recognised internationally that FCC is the cornerstone of children's nursing practice, it is not always implemented effectively or with consistency, as it depends on the perceptions held by those who are delivering care, the nursing staff, and those receiving that care, the children and parents/ guardians (Foster *et al*, 2010; Smith *et al*, 2015). There is a lack of clarity regarding the meaning of the concept of FCC among nurses (Murphy and Fealy, 2007; Coyne *et al*, 2011; Feeg *et al*, 2016; Boztepe and Kerimoğlu Yıldız, 2017; Peres de Oliveira *et al*, 2017; Coats *et al*, 2018) and the multidisciplinary team (Foster *et al*, 2010; Uniacke *et al*, 2018). It is also known that many parents of hospitalised children do not understand the meaning of the term (Coyne *et al*, 2011; Smith *et al*, 2015). Furthermore, there is evidence indicating that senior healthcare executives and policy makers do not clearly understand the meaning of the concept (Coyne *et al*, 2011). This widespread lack of clarity contributes to the recognised challenges to consistent and effective implementation of FCC in practice.

2.2 The importance of clarifying concepts in nursing

In professional terms, clarity of a concept is essential in order for a profession to further develop its existing scientific knowledge base (Weaver and Mitcham, 2008). A concept is an abstract or general idea (Collins English Dictionary, 2014). Walker and Avant (2011) describe a concept as a mental image of a phenomenon and not the phenomenon itself. Concepts are labels that describe phenomena and provide the main building blocks of knowledge. According to Rodgers (2000a) concepts are more than words or mental images, they are contextually and culturally based. Concepts play a significant role in our use of language and reason, and are expressed using the word(s) of interest.

The strength of a professional group is reflected in the development of a set of concepts relevant to its practice (Weaver and Mitcham, 2008). Concept clarification supports the development of professional confidence and competence (Holland *et al*, 2012), important attributes in any profession. The absence of a clear definition can lead to ambiguity, which can weaken one's understanding of a term and compromise how it impacts on the quality of care (Weaver and Mitcham, 2008). Clearly defined and understood concepts provide clarification, identification and a shared understanding amongst members of a profession (Baldwin, 2008). Clearly clarified concepts are necessary to define phenomena, describe situations and communicate effectively (Rodgers, 2000a). Furthermore the application of a clearly clarified concept allows for evaluation of the strengths and limitations of the concept to be measured, and its impact on practice to be described clearly. This process of

evaluation and re-evaluation guides further concept development and refinement over time (Rodgers, 2000a).

If knowledge is to develop from practice and become the emerging evidence-based practice, then clarifying concepts before proceeding with research is as important as clarifying operational definitions (Baldwin, 2008; Baldwin and Rose, 2009). Concept analysis is widely acknowledged as a form of inquiry to develop the knowledge base of nursing and other disciplines (Rodgers, 2000a). Concept analysis in nursing aids in the development of standardised language to describe nursing practice (Walker and Avant, 2011). Clarification can be accomplished by analysing the common use of the concept through the ways in which it is expressed, thereby identifying the cluster of attributes that constitute the concept (Rodgers, 2000a). Rodgers (2000a) contends that a clearly clarified concept may be used more effectively and its strengths and weaknesses evaluated. Variations can be introduced and tested, moving toward the development of a more useful concept, reflecting a contemporary context for its use.

2.2.1 Multidisciplinary working and professional language

Multidisciplinary working is a gold standard to which all healthcare professionals strive. Hence, it is important that all members of the multidisciplinary team understand each other's professional language, in order to optimise multidisciplinary team working and bring about the best possible health outcomes for patients and their families (Baldwin and Rose, 2009). True multidisciplinary and collaborative team working requires a commitment and careful attention to communication on the part of each individual team member. In order for optimum healthcare to be delivered, healthcare professionals must share a common understanding of discipline-specific language, knowledge and skills (Hull, 2016). Such a shared understanding of common terms avoids ambiguity and misunderstandings, leading to enhanced patient safety and quality healthcare. A study by Marshall *et al* (2011) recognised that making assumptions about the use of profession-specific language or 'jargon' when communicating with inter-professional colleagues may lead to misunderstandings between patients, families and professionals. Their study, which included semi-structured interviews with ten healthcare professionals representing six different disciplines, suggested that these misunderstandings can exclude the patient and their family from working collaboratively with the healthcare team in decision-making, resulting in less optimum health outcomes for the patient and their family. Marshall *et al* (2011; p. 453) concluded that:

"If professionals are unaware of the implications of language use with respect to practice, a collaborative healthcare approach that is inclusive of patients and their families is unlikely to develop."

For example, the use of the word “support” has a different meaning when it is used in different settings. In the oncology care setting, “support” may mean emotional support for the patient and family during the course of an illness, treatment and beyond. In the orthopaedic care setting “support” may mean the use of a brace or splint to support a joint following soft tissue injury or surgery.

2.3 The Irish context

Children's healthcare in Ireland is currently undergoing major reconfiguration with the development of a new children's hospital to replace the existing three children's hospitals in Dublin. Restructuring of clinical services is ongoing as the existing services amalgamate to provide a single tertiary healthcare service for the children of Ireland and their families. The aim of this restructuring process is to bring about a single service delivered across three sites, in advance of the new children's hospital becoming operational, which is expected in 2024. It is therefore timely to examine children's and parents' experiences and expectations of their roles while in hospital, in an attempt to develop a standardised approach to the delivery of nursing care across the three children's hospitals in Dublin and the wider Irish healthcare setting. A child is defined as a person under the age of 18 years (Government of Ireland, 2001). In the three children's hospitals in Dublin, children are accepted as in-patients up to the eve of their 16th birthday. In many cases, children whose treatment started prior to their 16th birthday will continue to be treated in the paediatric services until planned transition to adult services occurs. Children already attending with an existing chronic condition are accepted until they are satisfactorily transitioned to appropriate adult services. This may mean that occasionally some in-patients are older than 16 years of age. Transition of young people with a chronic condition to adult services requires planning and collaborative working between the young person, his/her family and both the paediatric and adult health services (Coyne *et al*, 2019). Ideally transition should be led by nurses and occur in a structured manner, within agreed protocols, often beginning from the age of 12 years (Royal College of Nursing, 2013; Coyne *et al*, 2019).

Nursing care in the three children's hospitals in Dublin is delivered within a FCC framework. FCC care has been described in the literature as a philosophy of care (Chenery, 2004; Murphy and Fealy, 2007; Harrison, 2010), an approach to care (Kuo *et al*, 2012; LeGrow *et al*, 2014) and a model of care (Casey and Mobbs, 1988; Hutchfield, 1999; Shields *et al*, 2007; Smith *et al*, 2015; Tallon *et al*, 2015; Curtis *et al*, 2016; Dennis *et al*, 2016; Uniacke *et al*, 2018). Evidence-based models of nursing care guide critical thinking and decision-making for professional nursing practice (Wood, 2013). They support nurses in the assessment, planning, implementation and evaluation of care, by providing a systematic evidence-based framework within which to deliver consistent, high quality patient care (Fawcett, 1995; McCrae, 2011). For the purpose of this analysis FCC will be referred to as

a model of care, since that is how it is described in most of the literature. Shields *et al* (2006: p. 1318) describe FCC as:

“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/ young person, and in which all the family members are recognized as care recipients.”

It is commonly acknowledged that the entire family is affected when a child is in hospital (Shields *et al*, 2006; 2007; 2012a).

2.3.1 Current international practice

FCC as a model of care is widely supported by nurses and healthcare professionals (Franck and Callery, 2004; Murphy and Fealy, 2007; Shields *et al*, 2007; Coyne *et al*, 2011; Tallon *et al*, 2015; Feeg *et al*, 2016). However its incomplete and inconsistent implementation is well documented (Bruce *et al*, 2002; Paliadelis *et al*, 2005; Petersen *et al*, 2004; Coyne *et al*, 2011; Smith *et al*, 2017), leading to much discussion throughout the literature around the challenges to its successful implementation (Ahmann, 2006; Shields, 2010; Bonavita *et al*, 2013; Coyne, 2013; Smith *et al*, 2015; Baird *et al*, 2015; Boztepe and Kerimoğlu Yıldız, 2017; Coats *et al*, 2018). Consequently, there has been commentary from some researchers suggesting alternative models of care (Tallon *et al*, 2015; Coyne *et al*, 2016). One such model is described by Tallon *et al* (2015) as a nurse-family partnership model emphasising respect, humility and reflective listening as the key components needed to build a trusting relationship with the child and family. Coyne *et al* (2016) described a child-centred care model, asserting that FCC needs to be re-directed towards a child-centred care approach, which promotes participation by the child in all aspects of his/her healthcare in collaboration with the family.

Although FCC is a term used frequently among children's nurses, the concept is not clearly defined or understood in the context of everyday practice. It could be argued that it has become a “catchphrase” and may have lost some of its meaning. According to Rodgers (2000a) many regularly performed activities often occur without an awareness of the real meaning of that activity, and so a concept can be performed without complete knowledge or clarity about its definition. People who use the concept may be unable to articulate its attributes and how it is appropriately applied in practice. A well-recognised barrier to the effective implementation of a family-centred model of care is this lack of a clear understanding of the concept and its key elements among nurses (Coyne *et al*, 2011; Feeg *et al*, 2016; Boztepe and Kerimoğlu Yıldız, 2017; Peres de Oliveira *et al*, 2017; Smith *et al*, 2017; Coats *et al*, 2018). There is also evidence that parents'/guardians' understanding of FCC may be unclear (Aein *et al*, 2011; Smith *et al*, 2015). Role confusion between parents' and nurses' perceptions of FCC has been described by some authors (Shields and Nixon,

2004; Stuart and Melling, 2014). Other studies report barriers for nurses when attempting to implement the concept of FCC (Paliadelis *et al*, 2005; Coyne *et al*, 2011). As identified earlier (in Chapter One) no single internationally accepted definition for FCC exists, rather different understandings of the concept have developed and a list of elements are described in much of the literature, contributing to the lack of clarity. When the definition and attributes of a concept are not clearly understood, the impact of the concept on practice is greatly impaired (Rodgers, 1989).

2.3.2 The need for a concept analysis

Together these findings suggest that while nurses endorse the concept of FCC, implementation of its principles into practice is more problematic (Paliadelis *et al*, 2005; Foster *et al*, 2010; Coyne *et al*, 2011). This suggests that there is considerable ambiguity about the phenomenon among parents/guardians, nurses and members of the multidisciplinary team. A lack of clarity about the operational meaning of FCC may lead to inconsistencies in how care is delivered, and uncertainty for families and staff. With this in mind it is timely that an analysis of the concept be undertaken to ascertain children's, parents'/guardians' and children's nurses' understanding of the concept of FCC for hospitalised children in an effort to provide clarity on the topic. The term is frequently used within the children's nursing community, and the academic nursing literature. Furthermore, several different terms are often used interchangeably to describe the concept, and it is highly relevant to children's nursing practice. Since nurses caring for children in hospital view FCC as the best model of care within which to deliver children's healthcare, a clear understanding of the essential elements is necessary to allow for its consistent and effective implementation.

2.4 Aim and objectives of the concept analysis

A concept analysis aims to provide a working definition and clarification of the concept being analysed (Rodgers, 2000a). This chapter aims to provide an operational definition of the concept of FCC for the purpose of this study. Rodgers' (2000a) evolutionary approach to concept analysis will be used as a guiding framework. To achieve this, the key objectives are to explore the meaning of FCC, and to provide clarification of the concept and its current use through a comprehensive analysis of the literature. Consensus within the literature of the key attributes will be identified, resulting in improved clarification and an enhanced understanding of the concept. In keeping with the aim of concept analysis as described by Rodgers (2000a) where the end product is a starting point for further research, this concept analysis will provide a foundation to enhance continuing concept development and further research, identifying what FCC means to the hospitalised child, his/her parent/guardian and children's nurses.

2.5 Method adopted to analyse the concept

Several methods of concept analysis exist with the shared goal of examining the literature to clarify the key characteristics or attributes of the phenomenon under review, and achieve a better understanding of its meaning (Wilson, 1971; Rodgers, 1989; Schwartz-Barcott and Kim, 2000; Rodgers, 2000a; Walker and Avant, 2011). Concept analysis focuses on clarifying a concept and its current uses by combining ideas from a range of existing sources in order to present common arguments, aiming to identify consistencies and inconsistencies in what is already known about the topic (Rodgers, 2000a). Rodgers (2000a) describes concepts as dynamic in nature rather than static, as context dependent rather than having a universal application without contextual variation, and as having a pragmatic use, arguing that human beings and related nursing phenomena are constantly changing. This description of concepts fits well with nursing in general, and particularly with the concept of FCC, which is dynamic, contextually and culturally dependent and is useful in a pragmatic way.

Five approaches to concept analysis were considered:

- a) **Wilson (1971)** uses a positivist approach, describing concepts as static in nature, unchanging regardless of their context, with an analysis pursuing a reductionist approach.
- b) **Rodgers (1989)** describes concept development as a continuous process of refinement which is contextually-based, proposing a seven-phase evolutionary concept analysis framework, contending that it is necessary to outline the antecedents and consequences, in order to fully understand the concept being analysed.
- c) **Schwartz-Barcott and Kim (2000)** propose a three-phase hybrid model of concept analysis which involves a theoretical phase, resulting in a working definition, a fieldwork phase where empirical data are collected, and a final analytic phase where the findings are analysed and reported.
- d) **Rodgers (2000a)** further developed her earlier framework outlined above, condensing the seven phases to four phases and adding two additional phases. In this revised edition, greater emphasis is placed on rigorous analysis and implications for further research and development.
- e) According to **Walker and Avant (2011)** the purpose of a concept analysis is to examine the structure and function of a concept. They describe an eight-step approach which includes identifying antecedents, consequences and empirical referents as components of the analysis.

When selecting an approach to concept analysis the nature of the concept and the purpose of the inquiry need to be considered carefully (Rodgers, 2000b). Rodgers (2000b) advises

that psychosocial concepts are more likely to be associated with greater ambiguity and variation in understanding than scientific concepts. Rodgers (1989) describes two views of concepts: the entity view and the dispositional view. The entity view focuses on a concept as an entity removed from context, the approach which both Wilson (1971) and Walker and Avant (2011) assume. The dispositional view emphasises the use of concepts in the real world of practice, where concepts are described as context-based and dynamic in nature. Rodgers (1989; 2000a) adopts a dispositional view when she describes the evolutionary cycle of concept development. The evolutionary concept analysis approach facilitates a concept analysis rooted in practice, and views concept development as an ongoing dynamic process. Given the changing and dynamic nature of FCC and children's healthcare globally, Rodgers (2000a) evolutionary concept analysis framework is considered to be particularly well suited to an exploration of FCC for children in hospital, and was used as the guiding framework for this analysis. An analysis of the concept of FCC of hospitalised children is outlined, an in-depth description of its attributes, antecedents and consequences is presented, and finally an operational definition of the term was described.

2.6 Rodgers (2000a) six-phase evolutionary method of concept analysis

2.6.1 Phase 1 - Identify the concept of interest

According to Rodgers (1989) a concept that is considered significant will be used often. It is this frequent use that can lead to the development of variations in definition and understanding. Over time a concept can become ambiguous or vague. Rodgers (2000a) contends that being familiar with relevant literature allows the researcher to identify the concept of interest and helps in selecting appropriate terminology. The literature indicates that FCC is considered the ideal way of caring for hospitalised children internationally (Coyne, 1996; Chenery, 2004; Franck and Callery, 2004; Shields *et al*, 2006; Dunst and Trivette, 2009; Coyne, 2013; Feeg *et al*, 2016). Although the term is used extensively in discussions pertaining to children's nursing, in both the spoken word and in the literature, it remains poorly defined with no agreement on a universally accepted definition. A clear understanding among children's nurses of the essential elements of FCC for children and their parents/families will support its consistent and effective implementation.

2.6.1.1 Phase 1a - Identify associated expressions including surrogate terms

Rodgers (2000a) describes surrogate terms as other words or phrases which are used interchangeably to describe the concept being examined. It is important to identify these surrogate terms early in the process as they may also be used during the search to aid in

the identification of samples to be included in the analysis. A review of the literature revealed that there are several different terms which are often used to describe FCC.

Partnership-in-care was first described by Casey (1988) as a model of care where the process of nursing is carried out in partnership with the child and family, with the nurse explaining how the partnership works; and together with the nurse, the child and the family decide to what extent they would like to participate in care. Casey (1988) asserts that parents can be educated and supported to gradually become involved in care, even in the intensive care setting. Since then *partnership-in-care* continues to be referred to in the literature frequently when FCC is being discussed (Coyne, 1996; Franck and Callery, 2004; Coyne, 2008a; Power and Franck, 2008; Foster *et al*, 2010; Smith *et al*, 2015; Dennis *et al*, 2016; Uniacke *et al*, 2018). Various other terms have also become synonymous with the concept, including *negotiated care* (Smith *et al*, 1995; Hutchfield, 1999; Shields, 2010), *care-by-parent* (Coyne, 1996), *parent participation* (Coyne, 1996; Franck and Callery, 2004; Power and Franck, 2008; Foster *et al*, 2010; Curtis *et al*, 2016) and *parental involvement in care* (Chenery, 2004; Mikkelsen and Frederiksen, 2011). *Child-centred care* (Söderbäck *et al*, 2011; Coyne *et al* 2016) appears in more recent literature related to FCC.

2.6.1.2 Phase 1b - Identify associated expressions including related concepts

Related concepts are “concepts that bear some relationship to the concept of interest but do not seem to share the same set of attributes” (Rodgers, 2000a; p. 92). Examples of such concepts are *person-centred care* (McCormack and McCance, 2006), *patient- and family-centred care* (Johnson and Abraham, 2012) and *patient-centred care* (Pickler and Tubbs-Cooley, 2014). However, these terms have broad applicability rather than being specifically child and family centric. Person-centred care describes a holistic approach to care where the patient and others significant to them are at the centre of care (McCormack and McCance, 2006). Johnson and Abraham (2012) describe patient- and FCC as an approach to care that promotes the development of a partnership between healthcare providers, patients, and their families, with an emphasis on collaboration with people of all ages, and in all healthcare settings. Patient-centred care is an approach to care where the patient is at the centre of care, participating in planning and evaluating his/her own care (Pickler and Tubbs-Cooley, 2014).

2.6.2 Phase 2 - Identify and select an appropriate realm (sample and setting) for data collection.

According to Rodgers (1989, p. 333) “the means of sampling has a significant influence not only on the rigour of the analysis but on the findings as well.” Rodgers (1989) advises that recording decisions about the selection of literature to be included in the analysis may

enhance the rigour of the analysis. A robust search strategy will ensure a sample of literature that is rigorously selected, will represent the literature fairly, with the rationale for all decisions recorded clearly, and ultimately minimise researcher bias (Rodgers, 2000a). A search strategy was designed in order to retrieve as many of the relevant published articles as possible. The advice of a dedicated subject librarian was sought to help in the development of an appropriate search strategy. Recognising that there can be significant differences in the language used to describe key words or terms, an initial search was conducted on the Cumulative Index of Nursing and Allied Health Literature (CINAHL) Complete database to identify appropriate control language using CINAHL Headings. Key search words/synonyms and terms related to the following five key concepts: “Children”, “Parents”, “Children's Nurses”, “Understanding” and “Family-centred Care” were also identified at this stage, through wide reading of the literature, by use of a Thesaurus and in consultation with professional and academic colleagues/supervisors (Appendix 2). Inclusion and exclusion criteria were developed in collaboration with academic supervisors (Appendix 3).

The nursing and allied health literature search engine, CINAHL Complete, was used for the initial search as it was expected to contain more relevant literature than other databases. Rodgers (2000a) suggests that this strategy helps to institutionalise the use of the concept within nursing. Combining data from different disciplines adds to the final clarification and promotes clarity among multidisciplinary colleagues. Once the search string was agreed and key search words and terms were developed, the literature search was conducted in March 2018. Using a combination of the keywords and control language based on the five key concepts outlined above, a search of the following four electronic databases was conducted: CINAHL Complete, Medline, PsycInfo and Embase. Boolean Operators, “OR” and “AND” were used. Searches were limited to English language publications only, and dated from January 2007 to March 2018. This timeframe was chosen to ensure that the articles retrieved were recent and relevant to the current children’s healthcare context. All articles were imported into EndNote Library, an electronic software tool for managing bibliographies, citations and references. As a selection of databases were searched it is common for duplication of articles to occur. Following removal of all duplicates, 21 articles remained. The titles and abstracts of these 21 articles were screened for relevance, following which 12 articles were excluded because they did not meet the inclusion criteria, resulting in nine articles for inclusion in the analysis following the first stage of the screening process.

Electronic searching is only the beginning of the process as it does not identify all published articles. To overcome this problem, the contents of a number of journals were searched, both through the electronic databases and by hand searching. Citations found in individual

articles were followed up. The purpose of this mix of search strategies is to ensure that, as far as possible, all relevant published research is identified. An additional 14 relevant articles were identified through searching the reference lists of the above nine articles, and a further 50 papers found through manual searching. Six articles published prior to 2007 were found during the manual searching process and were included in the analysis, as they were considered to be significant landmark works, which were cited frequently throughout the literature and may contribute to clarification of the concept. Once articles began to appear repeatedly during the searching process, and bibliographies were not yielding any new articles it was clear that the search was becoming exhausted. It was decided that adequate saturation of the available material had been reached, resulting in 73 articles for screening against the inclusion and exclusion criteria.

In recognition of the many theoretical papers already published on this topic, the need to examine them in detail and build upon this existing work, all theoretical papers which focused on analysing and developing the concept of FCC in the above cohort were included. Following full text screening of the above 73 articles, a total of 30 peer reviewed theoretical articles were identified for inclusion in this concept analysis. The search results are outlined on a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Flow Diagram (see Appendix 4). A summary of the characteristics of these 30 articles are detailed in Appendix 5 under the following five headings: Author/Year of publication, Setting/Country of origin, Design, Aim of paper and Key conclusions. All articles were retrieved from peer reviewed professional journals, the majority from nursing journals (22 of 30). This is not surprising since the analysis explores FCC as it applies to the nursing care of hospitalised children. Those articles not retrieved from nursing journals were published in professionally-oriented, interdisciplinary, peer reviewed journals or the Cochrane Database. All articles originated from developed countries, namely Australia, Canada, Denmark, Ireland, New Zealand, North America, Sweden and the United Kingdom (UK).

2.6.3 Phase 3 - Data analysis

According to Rodgers (2000a) the aim of data analysis in concept analysis is to identify a consensus in the literature. Data should be examined for areas of agreement/disagreement, changes over time and emerging trends which may indicate a need for further research. Once all relevant data were identified each item was read to obtain a general tone and sense of how the authors use the concept. This process also helps the researcher to become immersed in the topic (Rodgers, 2000a). Each article was then re-read. Data extraction records were maintained for each article during this second reading. Information regarding each of the major categories was recorded on a separate sheet of paper for each category: surrogate terms, attributes, antecedents and consequences. At

this point the discipline from which the data were generated, the country of origin and the year of publication were also recorded. Rodgers (2000a) cautions that the researcher must work hard to identify relevant data during the analysis phase and advises keeping in mind relevant guiding questions. Therefore, to guide this process questions were formulated for each category when examining the data, see Table 2.1 below.

Table 2.1 - Guiding questions used during the data analysis phase

Category	Guiding question
Surrogate terms	What other words say the same thing? Is this word/term referring to FCC?
Related concepts	Does this term bear any relationship to FCC?
Attributes	What are the characteristics of FCC as outlined in this paper? What is the author discussing/describing?
Antecedents	What is happening when FCC occurs? What happens before an instance of FCC occurs?
Consequences	What happens after an instance of FCC occurs? What happens as a result of FCC?

Formal analysis was not carried out until this process was completed in full for all papers. Delaying analysis in this way is helpful to avoid premature closure or “jumping to conclusions” (Rodgers, 2000a: p. 94). It also helps to minimise the impact of personal bias. Each category of data was examined separately, organising and re-organising data to identify consensus in the literature. In this way predominant themes emerged within the categories. Throughout this process data were examined for clarification as needed, this included re-reading articles for a third and subsequent time if necessary.

2.6.4 Phase 4 - Identify attributes, antecedents and consequences in the data

2.6.4.1 The attributes of family-centred care

Identifying the attributes of a concept by examining closely its most common uses aids in the clarification of a concept (Rodgers, 1989), and allows for recognition of occurrences of the concept of interest (Rodgers, 2000a). The following terms emerged from the literature as the attributes of FCC. *Parental participation in care* and/or *involvement in care* are referred to as fundamental elements in FCC across much of the literature (Coyne, 1996; Chenery, 2004; Dunst and Trivette, 2009; Mikkelsen and Frederiksen, 2011; Kuo *et al*, 2012; Smith *et al*, 2015; Dennis *et al*, 2016; Foster *et al*, 2016; Banerjee *et al*, 2018; Uniacke *et al*, 2018). *Care-by-parent* is referred to in some of the literature (Coyne, 1996; Foster *et al*, 2016), while Casey and Mobbs (1988: p. 67) recognised that families “participate in many aspects of care”. The idea of a *partnership* formation with the child, parents, family and the nursing team is frequently described (Casey and Mobbs, 1988; Coyne, 1996; Hutchfield, 1999; Chenery, 2004; Franck and Callery, 2004; Coyne, 2008a; Shields, 2010; Mikkelsen

and Frederiksen, 2011; Söderbäck *et al*, 2011; Kuo *et al*, 2012; Shields *et al*, 2012a; Dennis *et al*, 2016; Foster *et al*, 2016).

The development of *respectful and trusting relationships* as a factor enabling effective partnership development emerged as a sub-theme of partnership (Coyne, 1996; Dunst and Trivette, 2009; Harrison, 2010; Mikkelsen and Frederiksen, 2011; Kuo *et al*, 2012; Smith *et al*, 2015; Tallon *et al*, 2015; Banerjee *et al*, 2018). These respectful relationships between the child, the parents and family and the nurse were characterised by mutually agreed goals and a shared responsibility for the child's care (Mikkelsen and Frederiksen, 2011; Smith *et al*, 2015). In a review of qualitative studies on FCC Shields *et al* (2006) suggest a revised definition which includes *all family members as care recipients*. Foster *et al* (2010) and Shields *et al* (2012a) apply this definition to their work also. Landis (2007) refers to this idea, stating that the recovery process for the child and the family starts with caring for the family.

Information sharing with the child, parents and family (Dunst and Trivette, 2009; Tallon *et al*, 2015; Bedells and Bevan, 2016; Foster *et al*, 2016) and *empowering the family* to participate in informed decision-making about their child's healthcare, were other features which emerged frequently (Franck and Callery, 2004; Mikkelsen and Frederiksen, 2011; Kuo *et al*, 2012; Shields, 2017; Banerjee *et al*, 2018). Within this element the importance of *communication and negotiation* which promote the clarification of roles and responsibilities for each member of the partnership in order to avoid conflict was referred to by many authors including Coyne (1996), Shields *et al* (2006), Mikkelsen and Frederiksen (2011), Bedells and Bevan (2016), Dennis *et al* (2016) and Foster *et al* (2016). The key attributes and their associated contributing attributes are illustrated in Table 2.2.

Table 2.2 - Key attributes of family-centred care and their contributing attributes

Key attributes	Contributing attributes
Parental participation in care	<ul style="list-style-type: none"> • Parental participation in care • Parental involvement in care • Care-by-parent
Development of respectful and trusting partnerships	<ul style="list-style-type: none"> • A partnership formation with the child, family and the nursing team • The development of respectful and trusting relationships • Mutually agreed goals and a shared responsibility for the child's care
Information sharing	<ul style="list-style-type: none"> • Communication and negotiation • Patient and family empowerment
All family members as care recipients.	<ul style="list-style-type: none"> • Recovery process for the child and the family starts with caring for the family

It is worth noting that the term “parental participation” may no longer be appropriate. In the 1980s, when the term parental participation first appeared in the literature, Western society was different than it is today. Often extended family members lived near the hospitalised

child's family, and in many cases only one parent, most often the father, was working outside the home. Families are more diverse now than they were in the 1980s. There are significantly more single parent families, families with both parents working, same sex parents and families living remote from extended family (Central Statistics Office, 2017). Parents of hospitalised children may need to call on the help of close friends and/or extended family in order to support them during this period. If healthcare professionals are to subscribe fully to the concept of FCC, then care must reflect these societal changes. The healthy siblings at home must also be recognised as care recipients. Coyne (1996) commented that FCC may mean supporting the parents to remain with their other children in the home. In so doing we must welcome a significant other person, whom the child knows well and trusts, to the bedside. There is evidence that parents are empowered to participate in care when positive nurse-patient partnerships and knowledge sharing are in place (Hutchfield, 1999; Harrison, 2010). Hence, it is reasonable to assume that when a respectful and trusting nurse-parent relationship exists, where information is shared and roles are negotiated, parents will be empowered to participate in their child's care and decision-making while in hospital.

2.6.4.2 The antecedents of family-centred care

Rodgers (1989) suggests that the identification of antecedents will contribute to the clarification of the concept. The antecedents of a concept are those events that generally occur before occurrence of the concept. A number of antecedents which must be in place in order for FCC to occur were identified in the literature. These antecedents largely refer to the understanding, values and attitudes of nurses and parents of the concept of FCC and are linked to the presence of *parents at the bedside* of their hospitalised child (Casey and Mobbs, 1988; Chenery, 2004; Shields *et al*, 2006; Power and Franck, 2008; Mikkelsen and Frederiksen, 2011), and their *willingness to perform some aspects of their child's care* (Casey and Mobbs, 1988; Chenery, 2004; Shields, 2010; Smith *et al*, 2015). In order for true FCC to occur there must be a willingness on the part of *the staff to collaborate positively and respectfully with parents and families* and a commitment to share jointly the responsibility for care (Smith *et al*, 2015; Bedells and Bevan, 2016). *Open, honest, respectful communication and negotiation* must be in place to facilitate the development of an effective partnership relationship (Hutchfield, 1999; Coyne, 2008a; Foster *et al*, 2010). Hutchfield (1999) comments that *adequate time for communication* is an essential precursor of FCC in order to facilitate the teaching and supportive role of the nurse. Furthermore there must also be *flexible visiting arrangements and facilities for parents to be resident* (Hutchfield, 1999; Chenery, 2004) with their hospitalised child, as well as facilities for them to eat and rest during the day. The antecedents of FCC and their related attributes are illustrated on Table 2.3.

Table 2.3 – Antecedents of family-centred care and related attributes

Antecedent	Related family-centred care attributes
Parents at the bedside	<ul style="list-style-type: none"> • Parental participation in care
Parents' willingness to perform some aspects of their child's care	<ul style="list-style-type: none"> • Parental participation in care
Staff willingness to collaborate respectfully with parents and families	<ul style="list-style-type: none"> • Respectful and trusting partnerships
Open, honest, respectful communication and negotiation	<ul style="list-style-type: none"> • Information sharing • Respectful and trusting partnerships
Adequate time for communication	<ul style="list-style-type: none"> • Information sharing
Flexible visiting arrangements	<ul style="list-style-type: none"> • Parental participation in care • The family members as care recipients.
Facilities for parents to be resident	<ul style="list-style-type: none"> • Parental participation in care

A fundamental principle of FCC is the need to develop positive and respectful partnerships between hospitalised children, their parents and nurses. There is evidence that nurses are willing to engage in the development of such partnerships with patients and families. In a recent national consultation with Irish nurses, engaging in effective communication and developing a trusting and therapeutic nurse-patient relationship were identified as key behaviours associated with the core values of nursing (Department of Health, 2016). Hutchfield (1999) recognises that the development of these relationships and the implementation of FCC requires significant time on the part of the healthcare professional. Poor nurse-patient ratios and the associated busy nursing workload can be a barrier for nurses attempting to implement FCC practices (Curtis *et al*, 2016). Other factors such as the methods of organising and delivering nursing care, routine nursing tasks and the culture within the organisation may singly or in combination affect the implementation of FCC.

If FCC is to be fully and effectively implemented in practice and have benefits for all involved, then senior nurse managers and the executive management team in the organisation will need to work strategically to address such issues as workforce planning and organisational culture (Coyne, 2008a; Coyne *et al*, 2011; Coyne 2013). Furthermore, the education, training and skill development needs of nurses must be addressed through continuous professional development, so that nurses' knowledge of FCC and their skills in communication and negotiation are developed and maintained. Organisational policy must consider these fundamental requirements as well as the physical structures needed to support the consistent implementation of FCC in practice.

2.6.4.3 The consequences of family-centred care

Rodgers (1989) advises that the identification of consequences, those events that follow as a result of an occurrence of the concept, will help to add clarity to the concept of interest. There is no rigorous evidence to support the claim that FCC makes a difference to the health outcomes of children (Shields, 2010; 2015). Other authors support this statement, claiming that there is limited empirical evidence to support the benefits of FCC to either the

hospitalised child, their parents, healthcare professionals or to the healthcare organisation (Shields *et al*, 2007; Power and Franck, 2008; Harrison, 2010; Shields *et al*, 2012a; Shields *et al*, 2012b; Smith *et al*, 2015). More recently, in a systematic review of qualitative studies on the topic (Watts *et al*, 2014), limited evidence was found which values the parent being present with the child in hospital, these authors contend that FCC supports the parenting role during a child's hospitalisation. In another review of international literature by Curtis *et al* (2016) it was identified that reduced parental anxiety and increased parental satisfaction were associated with applying some elements of FCC to the care of critically ill children and their families. Other than these reviews (Watts *et al*, 2014; Curtis *et al*, 2016), the consequences of FCC are founded on assumptions, rather than empirical evidence. Positive consequences are based on the assumption that hospitalised children, their families and healthcare organisations benefit from a family-centred approach to care (Hutchfield, 1999). In a literature review of international publications Curtis *et al* (2016) conclude that a family-centred approach to care enhances the child's, parents' and families' experience of hospitalisation and is associated with reduced anxiety for parents. Dunst and Trivette (2009) report improved parent and child wellbeing as a consequence of effectively implemented FCC. Support for parental roles and a shared responsibility for the child's care were associated with parental empowerment in much of the literature (Power and Franck, 2008; Dunst and Trivette, 2009; Mikkelsen and Frederiksen, 2011; Kuo *et al*, 2012; Bedells and Bevan, 2016; Foster *et al*, 2016; Banerjee *et al*, 2018). According to other authors parents participating in their hospitalised child's care is associated with increased parental satisfaction with care (Shields *et al*, 2012a) and cost effectiveness (Shields *et al*, 2006; Harrison, 2010; Shields *et al*, 2012a).

Less positive consequences of FCC have been described by Darbyshire (1995), Power and Franck (2008) and Foster *et al* (2016), claiming that anxiety and stress are common among parents caring for their child in hospital. The expectation that parents must be constantly present at their child's bedside and participating in care was noted by Power and Franck (2008), Mikkelsen and Frederiksen (2011) and Foster *et al* (2016). Shields *et al* (2006) argue that this expectation by healthcare professionals can lead to *financial and emotional stress for a family*. Curtis *et al* (2016) note that some parents feel *confused by the medical jargon* used, which limits their understanding of their child's condition. These authors go on to comment that some healthcare professionals believe that some parents were not always able to carry out the agreed child care activities, which can lead to conflict.

2.6.5 Phase 5 - Identify an exemplar of the concept of family-centred care

Describing an exemplar provides a practical demonstration of how the concept might appear in real life. The goal of this exercise is to illustrate the attributes of the concept in

context, and to enhance its clarification and consistent use (Rodgers, 2000a). Identifying an exemplar from the literature or from practice is recommended above constructing an exemplar, which can introduce the risk of bias (Rodgers, 2000a). An additional search was conducted seeking to find an example of FCC of hospitalised children, but the search failed to yield a suitable case. This finding could point towards a lack of clarity and a poorly developed concept explaining the difficulties about its application in practice, which is described frequently in the literature. Rodgers (2000a) warns the researcher to avoid constructing an exemplar at this stage, as it may give an impression of a clearer and more developed concept than is truly the case. As the author was unable to identify a model case from the literature, and in an effort to avoid constructing an exemplar, a real life case from the author's own clinical practice experience was identified and is described below.

Exemplar case (*All names have been altered to ensure anonymity*)

Jane, a 12 year old girl, was in hospital having been recently diagnosed with acute myeloid leukaemia. This was her first time in hospital. Following her first course of chemotherapy Jane developed stomatitis and, despite around-the-clock pain relief and two-hourly mouth care, was unable to eat or drink sufficiently in order to maintain optimum hydration and body weight. Anne, Jane's mother, usually stayed with her, but had returned home to be with the other children for two days. Jane's grandmother, Mary, was staying with her during this time.

Jane and Mary knew me well. Previously I had explained how the philosophy of care within the unit was family-centred and explained the facilities for parents/family members staying with their children. We discussed what care Jane and Anne were happy to participate in, with support from nursing staff. Mary was keen to be involved in as many aspects of Jane's care as possible in order to minimise the adverse psychological effects of hospitalisation for Jane. I had already confirmed that Mary was competent in checking Jane's temperature via the axillary route using the hospital's electronic thermometer and that she knew how to record same on the Observation Record. Jane was happy and competent in maintaining her own oral intake record and recording her urinary output and bowel movements, with support from her grandmother and nursing staff. Together, following guidance and with ongoing support, Jane and Mary wanted to carry out the required two-hourly mouth care. I also updated Mary and Jane on the care plan, which I had developed previously, and shared with Anne and Jane.

On this day Jane had not been able to eat her breakfast, and had refused a mid-morning offer of strawberry yogurt, her favourite. Jane had lost more than one kilogram in body weight since her admission, 10 days earlier. Since this was only the beginning of her chemotherapy treatment, it was likely that she would not be able to maintain her body weight during the prolonged treatment. I explained to Mary, and to Jane in child appropriate language, that weight loss contributes to other complications, such as being more prone to infections and a lack of energy for play activities. I suggested that Sandra, the dietician working on the unit, would call to see Jane and advise on possible options.

Together with Sandra, Jane, Mary and I discussed Jane's poor oral intake over the previous two days, the associated weight loss and the consequences of same. The alternatives to promote weight gain were also discussed, such as the insertion of a nasogastric tube for supplemental feeding or commencement of intravenous total parenteral nutrition. The benefits and risks of both were discussed. Neither option appealed to Jane, who suggested instead that she would try to eat and drink more during the afternoon. We all agreed to this plan and that we would observe Jane's intake and output closely until 16.00hrs that day. We would all review the situation then. During the early afternoon Mary and Jane spoke with Jane's mother at home, explaining the situation and the options. All three expressed a preference for the nasogastric tube and supplemental feeding option, if there was no improvement in the intake by 16.00hrs.

At 16.00hrs Sandra and I went to Jane's room to review her intake and output with Jane and Mary. While Jane had made a definite effort to drink, she was not able to drink sufficiently to maintain hydration. She was unable to eat any solid food during the afternoon. We agreed to insert a nasogastric tube, but first Jane wanted to speak to her Mum again. I demonstrated the procedure on the ward mannequin so that Jane would know what to expect and be less frightened by the procedure. I also offered to speak with Anne on the phone if Anne wished.

At approximately 17.30hrs I inserted the nasogastric tube with help from both Mary and Jane. In fact Jane was able to slide the tube into position, while I secured it. Sandra developed a feeding plan and discussed it with both Jane and Mary. I suggested that Jane get used to the feel of the tube before we commenced feeding. I updated Jane's care plan and informed Jane and Mary of these updates. Feeding was commenced via the tube at about 19.30hrs.

In the above example the author attempts to develop a respectful and trusting partnership with Jane and her grandmother through negotiation, information sharing and mutual respect for the skills and knowledge that they both have. Through clear communication we understood each other's role. Meaningful parent/grandparent participation in Jane's care was supported safely. Goals and shared responsibility were reached through consensus. Mary and Jane were empowered to carry out agreed care activities safely. Accommodation for family members was also available to Jane's grandmother, allowing Jane's mother to return home to be with other members of their family. While this exemplar demonstrates most of the attributes of FCC identified in this analysis, there are some areas of practice which need further development. Jane and Mary were not given the opportunity to develop/update Jane's care plan in a truly participative fashion. Both the author and the dietician developed and updated the care plans without input from Jane or Mary, only sharing the completed work with them afterwards. If the care plan is to act as a contract between the family and the nurse as Coyne (1996) suggests, then it must be developed and co-signed by all parties who take a shared agreed responsibility in ensuring it is carried out in full.

2.6.6 Phase 6 - Implications for practice and further development of the concept

Identifying implications for further inquiry is a significant outcome of this approach to concept analysis. Rodgers (2000a) cautions the researcher not to expect the findings to be applied immediately, instead advising that the results be applied and tested as another phase in the continuing cycle of concept development. Following application, the concept is evaluated and re-evaluated to assess its contribution to practice and promote further concept development.

2.6.6.1 The impact of shorter hospital stay on family-centred care

The articles included in this analysis were published between 1988 and 2018 and focused on FCC in relation to the hospitalised child. Over that time healthcare practices have changed dramatically, with increased day-case activity, both medical and surgical, and shorter hospital length of stay (Department of Health, 2017). These changes have many important benefits including shortening hospital waiting lists, allowing for more efficient use of healthcare resources, both financial and human, increasing bed capacity and reducing the risk of healthcare-associated infections. However, it is important to note that day case procedures and a shorter hospital stay result in less time for both the nurse and the family to develop a partnership relationship, and consequently for the parents to acquire the knowledge and skills necessary to care for their child at home. Equally the faster turn-around of patients within a clinical setting limits the nurses' opportunities to acquire any deep knowledge about the child and his/her family, which enhances individualised care. The real cost to families of having the responsibility of caring for their child at home following a day case procedure or early discharge, and with only limited time to receive education and support from nursing staff, is not yet known. Further research is needed to examine what this emerging phenomenon means for families, in light of the current social context and changing family dynamics.

2.6.6.2 The influence of culture

The influence of culture has not been well examined in the literature. This lack of attention to culture limits our understanding of FCC across culturally diverse settings (Dennis *et al*, 2016). Societies nowadays are culturally diverse, with international job opportunities available in many careers. What was once known as the Western world is now populated by many people from developing countries, seeking a better standard of living for themselves and their families. While all of the articles in this analysis were derived from the "Western world", it is reasonable to assume that many people living in these countries today are from very different cultural backgrounds. The number of Irish residents born outside

Ireland continues to increase with every census (Central Statistics Office, 2017). In a recent national consultation process Irish nurses identified compassion as one of the three core values of nursing, while respecting cultural sensitivity and diversity is recognised as an associated behaviour (Department of Health, 2016). Future research must examine FCC from the child's and parents' perspectives and attempt to include culturally diverse children and parents as research participants.

2.6.6.3 Patient- and family-centred research

It has been highlighted in many of the articles included in this analysis that there is limited evidence examining the benefits, or otherwise, of FCC to either the hospitalised child, their parents and families, to nurses or to healthcare organisations (Power and Franck, 2008; Harrison, 2010; Shields, 2010; Shields *et al*, 2012a; Shields *et al*, 2012b; Smith *et al*, 2015). It is also well recognised that there are several barriers to its effective implementation (Bruce *et al*, 2002; Paliadelis *et al*, 2005; Coyne *et al*, 2011; Feeg *et al*, 2016; Boztepe and Kerimoğlu Yıldız, 2017; Peres de Oliveira *et al*, 2017; Smith *et al*, 2017; Coats *et al*, 2018). Effective implementation is dependent on the development of research and theory, provision of education, and support for practice, all of which can only be achieved with adequate funding. Financial accountability is an expectation of all publicly funded organisations, including healthcare. Funding is prioritised for allocation to those areas of clinical practice where there is robust empirical evidence of effectiveness, assuring healthcare executives of its benefits, not only to hospitalised children and their families, but also to healthcare organisations. The use of such empirical evidence contributes to the goals of quality and safety in healthcare (Alligood, 2013).

Pickler and Tubbs-Cooley (2014) argue that although nurses have supported patient-centred care for many years, healthcare research is not patient-centred because it fails to include the measurement of outcomes that matter most to patients and their caregivers. Patient-centred research must have:

“Patients, caregivers, and other stakeholders as integral members of the research team from the inception of the research question to the dissemination of the research findings”
(Pickler and Tubbs-Cooley, 2014: p. 103).

If children's nurses are serious about implementing FCC consistently, then empirical evidence must be generated, which must incorporate the views and expectations of children, parents and families who are care recipients in order to secure the necessary funding for the associated educational, implementation and operational costs. Further research must examine outcomes of FCC on children, their parents and families. These outcomes may include the effect of FCC on parents' ability to care for their child in hospital, on supporting parents to make healthcare decisions and on health outcomes.

2.7 The emergent operational definition

Following this analysis of the concept of FCC the emergent operational definition for the purposes of this study is:

FCC occurs when parents are supported to participate in the care of their child in hospital. It is facilitated when information is shared between the child, the parent/family and the nurse in an open and honest manner, and in language that is easily understood. FCC promotes the development of a respectful and trusting partnership between the child, the parent/family and the nurse, and recognises that the entire family are recipients of care.

According to Rodgers (2000a) a concept analysis is only a starting point for further research and continuing concept development. Identifying what FCC means to the hospitalised child and his/her parent/guardian and family will support the effective and consistent implementation of the concept in practice. This concept analysis was published in the *Journal of Clinical Nursing* (O'Connor *et al*, 2019), and is available at <https://doi.org/10.1111/jocn.14913>. It was also presented as oral and poster presentations at nursing conferences nationally. Disseminating research in this way helps to inform the children's nursing community, both academic and clinical, and promote a better understanding of the concept and its attributes for hospitalised children and their parents.

2.8 Limitations

While the search strategy for this concept analysis seemed exhaustive, some relevant articles may have been missed, particularly landmark articles which were published prior to 2007. Although manual searching was carried out, it is not possible to be sure that all published articles on the topic were found. Furthermore, as only peer reviewed theoretical papers were included, it could be considered a limitation that grey literature was not included. Despite these limitations the analysis of the included articles resulted in identification of attributes which are consistent with previous analysis of the subject.

2.9 Conclusion

Concept analysis is never an end in itself; rather it is a means towards further concept development. If concepts are to be developed, they must be rooted in empirical knowledge and must be tested (Risjord, 2009). In order to continually develop nursing knowledge and evaluate its impact on the quality of patient and family health outcomes, nursing needs to develop and agree consistent universal language on key concepts. Nursing interventions must be measured and their impact communicated, not only among nurses but also to the wider healthcare community of medicine, allied healthcare professionals and healthcare administrators. Effectiveness and appropriateness of nursing interventions are of interest to healthcare executives as they continue to be faced with the dilemma of providing cost-

efficient, yet quality healthcare and a commitment to demonstrating sound financial accountability.

There is a need to rigorously evaluate FCC to identify its impact on child health outcomes, the experience of parents and to support its continued use (Curtis *et al*, 2016). Such an evaluation will be valuable when seeking funding to support consistent and effective implementation of FCC in practice. Children's nurses have been applying elements of FCC in their clinical practice for decades. However the concept of FCC continues to evolve. Equally the context within which we organise and deliver health services, specifically nursing, is continuously evolving. Further research will need to examine the impact of FCC in the evolving context of the current health services and society. Using nursing's empirical knowledge in practice, guides reasoning and decision making for nurses to practice in a logical and organised manner (Alligood, 2013). Healthcare professionals must be fully informed about what difference FCC makes to the health outcomes for the child and family, and how it is best implemented, if we are to move away from the current *ad hoc* implementation of the model to a more systematic and evidence-based approach.

2.10 Chapter summary

This chapter outlined the analysis of the concept of FCC for children and young people in the acute hospital setting using Rodgers (2000a) approach to concept analysis. The search strategy, which applied systematic principles, was described and the results presented using a PRISMA flow diagram (Appendix 4). The implications for further research and concept development were discussed. Finally an operational definition was presented. Chapter three will present a review of the literature in order to seek deeper insights into how FCC is implemented for hospitalised children and their parents.

Chapter 3

Literature Review

“Family centred care is complex, relational, dynamic and subject to the influence of many internal and external factors.”

(Carter, 2008).

3.1 Introduction

Family-centred care (FCC) has been a central tenet of children's nursing in the Western world for many decades and is described in the literature as a philosophy of care (Chenery, 2004; Murphy and Fealy, 2007; Harrison, 2010), an approach to care (Kuo *et al*, 2012; LeGrow *et al*, 2014) and a model of care (Casey and Mobbs, 1988; Hutchfield, 1999; Shields *et al*, 2006; Shields *et al*, 2007; Smith *et al*, 2015; Tallon *et al*, 2015; Curtis *et al*, 2016; Dennis *et al*, 2016; Uniacke *et al*, 2018). For the purpose of this literature review FCC will be referred to as a model of care, since that is how it is described in most of the literature. FCC has been defined as:

“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/young person, and in which all the family members are recognised as care recipients” (Shields *et al*, 2006; p. 1318).

The central premise of FCC in children's nursing is that the child's family is a constant and is comprised of the most important people in the child's life. It is commonly acknowledged that the entire family is affected when a child is hospitalised (Shields *et al*, 2007; Shields *et al*, 2012a). A child's illness and hospitalisation are recognised as stressful situations both for the child and for the parents (Aftyka *et al*, 2017). Families, specifically parents, provide support, comfort and reassurance to their child during times of stress (Kamerling *et al*, 2008; Meltzer *et al*, 2012; Matziou *et al*, 2018). Respecting and supporting the role of parents and family during a child's hospital stay is fundamental to FCC.

FCC as a model of care is widely supported by nurses and healthcare professionals working with children (Coyne *et al*, 2011; Tallon *et al*, 2015; Feeg *et al*, 2016). However, the incomplete and inconsistent implementation of FCC is well documented, particularly within children's nursing (Bruce *et al*, 2002; Paliadelis *et al*, 2005; Petersen *et al*, 2004; Coyne *et al*, 2011; Smith *et al*, 2017), leading to much debate about the challenges to its successful implementation (Ahmann, 2006; Shields, 2010; Bonavita *et al*, 2013; Coyne, 2013; Smith *et al*, 2015; Baird *et al*, 2015; Boztepe and Kerimoğlu Yıldız, 2017; Coats *et al*, 2018). Confusion about roles and expectations of FCC held by parents and nurses has been described by some authors (Coyne, 1995; Shields and Nixon, 2004; Stuart and Melling, 2014).

3.2 Recent reviews

A number of literature reviews examining various aspects of FCC have been published over the past decade. Foster *et al* (2010) reviewed literature on the attitudes and experiences of FCC by healthcare professionals and parents of hospitalised children. They found that

communication between staff and families was one of the most important factors facilitating effective FCC and concluded that a lack of knowledge and/or resources were common issues which contributed to the *ad hoc* implementation of FCC in practice. Two systematic reviews of FCC for hospitalised children aged 0-12 years (excluding premature neonates) were published in 2012 (Shields *et al*, 2012a; Shields *et al*, 2012b). In a systematic review of quasi-experimental studies (Shields *et al*, 2012a), only one study met the inclusion criteria, so the authors were unable to make any firm conclusions about the effectiveness or otherwise of FCC for hospitalised children and their families. The second by Shields *et al* (2012b) was an update of the Cochrane systematic review of randomised control trials (Shields *et al*, 2007). Again only one study was identified which met the inclusion criteria. The authors concluded that further research should assess the effects of FCC on hospitalised children's and their parents' experience of care (Shields *et al*, 2012b). A systematic review of qualitative studies (Watts *et al*, 2014) identified 14 studies which met the inclusion criteria. This review confirmed that parents want to participate in caring for their sick child in hospital but the extent to which they wish to do so must be negotiated with each individual parent. The authors concluded that while healthcare professionals appear to have a good understanding of what constitutes FCC, its application in practice is inconsistent.

Other literature reviews examined primary research on FCC of children in the paediatric intensive care unit (PICU) (Butler *et al*, 2014; Curtis *et al*, 2016; Hill *et al*, 2018a). Butler *et al* (2014) found that the PICU environment posed many challenges to FCC, but that nurses were ideally placed to promote positive relationship building and information sharing, as well as to act as an advocate for the child and family in PICU. These authors were unable to find any research which looked at “the impact of contextual or cultural factors on the practice of FCC in PICU” (Butler *et al*, 2014; p. 2097), and concluded that further research into FCC in the PICU setting was needed to ensure that practice is evidence-based. Curtis *et al* (2016) reviewed the literature on the impact of a family-centred model of care for children requiring PICU admission. They found that applying the principles of FCC can result in improved communication between parents and the healthcare team and reduced anxiety levels for parents. However, “feeling confused by medical jargon” (Curtis *et al*, 2016: p. 333) which led to a lack of knowledge about the child's condition and plan of care was also reported, and was associated with increased levels of anxiety for parents. Only one or two aspects of FCC were applied in practice. Curtis *et al* (2016) concluded that a model of care which can be applied holistically across the entire healthcare journey, from admission to discharge, is needed for the child with a critical illness and his/her family. More recently Hill *et al* (2018a) reviewed empirical studies which examined how parental involvement in their child's care in PICU reflected the four core concepts of FCC as outlined by the Institute for Patient- and Family-Centered Care's (IPFCC): respect and dignity, information sharing,

participation and collaboration. They identified that parents felt both negative and positive experiences of FCC when their child was in PICU. The use of everyday language to communicate with parents instead of medical jargon was reported to promote understanding, while allowing unrestricted visiting by parents and encouraging them to perform basic care activities was viewed as a form of respect and dignity. These authors concluded that future research was needed to examine healthcare professionals' knowledge and understanding of FCC in order to better understand its inconsistent implementation in practice.

3.3 This review

A literature review, applying systematic principles, was undertaken to build a deeper understanding of the topic. A critical examination of the recent relevant literature, to establish a deeper insight of the phenomenon under review, is not possible from the data in a single study (Sutton *et al*, 2019). It also demonstrates that the writer has extensively reviewed and critically analysed the existing literature (Grant and Booth, 2009; Sutton *et al*, 2019), and provides the reader with a comprehensive understanding of the topic (Cronin *et al*, 2008). Gaps or inconsistencies in knowledge and areas for further research activity are identified, typically resulting in a research question (Munn *et al*, 2018). An objective of such a review is to demonstrate what work has already been completed in the subject area and what research methods and theories were predominantly used. It is commonly used in qualitative research and helps to direct further original research to address existing gaps and support the research question.

Previous reviews on FCC have reported findings from articles where the healthcare professionals' and/or parents' perceptions are represented (Foster *et al*, 2010; Shields *et al.*, 2012a; Shields *et al*, 2012b; Butler *et al*, 2014; Watts *et al*, 2014; Curtis *et al*, 2016; Hill *et al*, 2018a). In one review the authors (Butler *et al*, 2014) found only one paper which included the views of the hospitalised child. An earlier review by Coyne (2008b) found that hospitalised children had varying experiences of being involved in and being consulted with in decisions about their own healthcare and they experienced less than optimal communication. However, the focus of Coyne's (2008b) review was not specifically on hospitalised children's experience of FCC.

This present literature review differs from previous reviews as it focuses on primary research studies examining FCC from the perspective of the child, parents, family and healthcare professionals during a 12-year timeframe from January 2007 to December 2018. It builds upon previous reviews on the topic by critiquing recent, relevant, primary research, including qualitative, quantitative and mixed methods studies. It focusses on the views and experiences of FCC from the perspective of hospitalised children, their parents and family, and the nurses caring for them. The aim was to bring together primary research evidence

to create a deeper understanding of FCC for hospitalised children and their parents. The objective is to provide a critical analysis and synthesis of identified international empirical studies on FCC, identifying any knowledge gaps and areas for further research. Reviewing qualitative, quantitative and mixed methods studies in a single literature review, known as a mixed studies review, is particularly suited to healthcare reviews as it can address complex questions and “provide a rich detailed and highly practical understanding of complex health interventions” which are more relevant and useful for busy healthcare professionals (Pace *et al*, 2012; p. 48).

A literature review was conducted to obtain a comprehensive understanding of current knowledge on the topic (Cronin *et al*, 2008), identify gaps or inconsistencies in existing knowledge, and areas for further research (Munn *et al*, 2018).

3.4 Method

3.4.1 Search and selection strategy

The search strategy aimed to conduct a search that was exhaustive and representative of all studies that have been conducted on the topic to date (Papaioannou *et al*, 2010). A clear search and selection strategy is necessary for any literature review in an attempt to retrieve as complete a list as possible of all the published articles relating to a particular subject (Cronin *et al*, 2008). Clear documentation of the search strategy is important to ensure robustness and reproducibility. Outlining the inclusion and exclusion criteria ensures the quality and similarity of the studies included in the review, and defines the boundaries of the review (Siddaway, 2014).

Inclusion and exclusion criteria were developed to aid in the identification of the articles to be included (see Appendix 6). All articles had to be peer-reviewed primary research studies and published in English between January 1st 2007 and October 4th 2018. Studies had to report on FCC from the perspective of hospitalised children, parents/ families and nurses. This 12-year period was chosen to reflect the most recent research and to ensure the articles retrieved were relevant to current practice as it applies to the care of hospitalised children and their parents. For the purposes of this review children includes infants from birth to 16 years of age, but excludes sick neonates in the neonatal intensive care unit (NICU) setting and young people over 16 years of age. Only articles which addressed the care of children and their families as in-patients in the acute hospital setting were included, articles focussing on day-care, emergency care, residential care or other settings were excluded. The parent includes the primary figure acting in the parental role. It may be the natural or adoptive parent, step-parent, foster parent, grandparent or any other adult figure acting as guardian to the child. From this point the word “parent” will refer to any of the aforementioned persons acting in the role of parent to a child in hospital.

Identification of keywords to aid literature searching needs careful consideration in order to select terms that will identify appropriate articles for consideration (Cronin *et al*, 2008). The development of keywords was guided by a concept analysis on the topic which had been conducted previously (see Chapter 2). The assistance of a subject librarian was sought to ensure the literature search was conducted systematically and with integrity. The databases were searched on 4th October 2018 and included: Cumulative Index to Nursing and Allied Health Literature (CINAHL) Complete, MEDLINE and PsycInfo. The search terms used are outlined in Appendix 7 while the search results are outlined in Table 3.1 below. The asterisk operator (*) was used to help find variant spellings for words during the searching process. The outcome of the screening process and the number of articles considered eligible for inclusion in the review following the original search are illustrated using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram, see Appendix 8.

Table 3.1 - Outcome of Database searches

Database	Articles retrieved
CINAHL Complete	1447
MEDLINE	842
PsycInfo	271
Total	2560

Following removal of duplicates (n=662), the title and abstract of all remaining papers (n=1898) were reviewed. In light of the wealth of literature retrieved on the topic, only reports of primary research studies were included. Following review of the title and abstract of all 1898 papers, a total of 151 studies were deemed suitable for full text screening. At this stage a manual search of the reference lists was carried out, which yielded no further new studies, indicating that the search had been exhausted. Following full text screening of 151 articles, 45 primary studies were included in the review: 22 qualitative, 18 quantitative and five mixed method studies. Table 3.2 below outlines the country of origin and the research method of the included studies.

Table 3.2 - Country of origin of studies included in literature review

Country of origin	Number of studies	Qualitative research	Quantitative research	Mixed methods research
Australia	2		1	1
Brazil	2	2		
Canada	3	2	1	
China	1	1		
Denmark	1		1	
Greece	1		1	
Iran	3	1	2	
Ireland	3	1	2	

Table 3.2 continued - Country of origin of studies included in literature review

Country of origin	Number of studies	Qualitative research	Quantitative research	Mixed methods research
Italy	1		1	
Jordan	1		1	
Netherlands	1	1		
New Zealand	2	2		
Nigeria	1		1	
Saudi Arabia	1			1
Switzerland	1			1
Thailand	1		1	
Turkey	3	1	2	
United Kingdom (UK)	5	5		
United States of America (USA)	11	6	3	2
Australia, Turkey and the USA	1		1	
Total	45	22	18	5

Ten studies were conducted in the critical care setting, one study in both general ward areas and in the PICU setting, one in the oncology setting, one in a respite setting while all remaining studies (n=32) were based in the general children's ward setting. Three qualitative studies included data from children, parents and nurses or healthcare professionals (Coyne and Cowley, 2007; Coyne, 2013; Curtis and Northcott, 2017), while two qualitative studies (Livesley and Long, 2013; Rasmussen *et al*, 2017) included data from children only. Eleven studies, four qualitative, six quantitative and one mixed methods study, included data from both parents and nurses or healthcare professionals. Of the 29 remaining studies, 17 included data from parents only (eight qualitative, six quantitative and three mixed methods), while 12 studies included data from nurses only (five qualitative, six quantitative and one mixed methods).

3.4.1.1 Updating the literature search

On October 26th 2022 the literature search was updated to include any new publications which met the inclusion criteria since October 4th 2018. The same search terms were used and the same databases were searched, see Appendix 7. Limits were set to include articles from 2018 to 2022 only. The outcome of the updated database searches are outlined below in Table 3.3.

Table 3.3 - Outcome of database searches following updated search

Database	Articles retrieved	Articles removed after de-duplicating, reading titles and abstracts	Articles remaining	Articles removed after full text reading	Articles included in updated search of the literature
CINAHL Complete	607	532	75	63	12
MEDLINE	565	501	64	59	5
PsycInfo	136	128	8	8	
Totals	1308	1161	147	130	17

Following removal of duplicates, the title and abstract of the remaining papers were reviewed based on the pre-defined inclusion and exclusion criteria as outlined in Appendix 6. A total of 147 studies were deemed suitable for full text screening. No further new studies were identified following a manual search of the reference lists, indicating that the search had been exhausted. Following full text screening of 147 articles, 17 primary studies were added to the review: nine qualitative studies, six quantitative studies and two mixed method studies. See Appendix 9 for an outline of the 147 articles retrieved and read following this updated search, including the reasons for exclusion.

Of the additional studies included in the review, 14 were conducted in general ward areas in the acute children's hospital setting, while the remaining three studies were conducted in critical care areas. Five studies included data from parents only: three qualitative (Fisk *et al*, 2022; Phiri *et al*, 2020; Terp *et al*, 2021) and two quantitative (Khaksar *et al*, 2022; McCann, 2018). A further five studies included data from both parents and nurses: three qualitative (North *et al*, 2020; Saria *et al*, 2019; Vasey *et al*, 2019) and two quantitative (Farokhzadian *et al*, 2021; Foster *et al*, 2018). The remaining seven studies included data from nurses and/or healthcare professionals only. No studies included data from children. Table 3.4 outlines the country of origin of the studies and the research method used. In total 62 studies (45 studies from the original search and 17 studies from the updated search) were included in this review.

Table 3.4 - Country of origin of additional studies following updated search

Country of origin	Number of studies	Qualitative research	Quantitative research	Mixed methods research
Australia	1		1	
Ghana	1	1		
Iran	2		2	
Jordan	1		1	
Malawi	3	2	1	
South Africa	1	1		
Sri Lanka	1			1
Sweden	1	1		
Tanzania	1	1		
Thailand	1			1
UK	1	1		
USA	3	2	1	
Total	17	9	6	2

3.4.2 Data extraction

The process of systematically extracting and synthesising data from various studies allows for robust reporting of the findings, their implications for practice and further research activity (Munn *et al*, 2014). By using standardised data extraction tools data, both descriptive and outcome data, relevant to the review question are extracted objectively across all the included studies. The use of a standardised data extraction tool, regardless of the studies' methodology, and two independent reviewers bring different perspectives to the findings,

enhances transparency, minimises bias, adds to the validity of the review (Siolemezi and Linceviciute, 2018) and helps to minimise errors in data extraction (Lockwood *et al*, 2017).

Each individual study was read at least once to gain an understanding of what the author(s) had investigated and their findings. Data extraction was carried out on the 62 studies by the primary researcher using an amended version of the Joanna Briggs Institute (JBI) Data Extraction Form for Systematic Reviews (Lockwood *et al*, 2017). Extracted information included such items as the author(s) and year of publication, the aims/objectives of the study, the characteristics and number of participants and how they were recruited, the country of origin and contextual setting of the study, type of study and methodology, data collection and analysis methods, the key findings and implications for practice and research. By extracting data in this way a logical and descriptive summary of the results of each study was aligned with the objectives of the review and the review question. Completed data extraction forms were reviewed by two research supervisors, agreement was reached through discussion and consensus. Appendix 10 is an example of three completed data extraction forms. It is important to become immersed in the data before beginning data analysis. Notes were made at this stage about similarities and differences, paying particular attention to study findings. A summary of the studies included in this review are outlined in Appendix 11.

3.4.3 Assessment of methodological quality

Critical appraisal is an objective structured appraisal of a research study, leading to a clear understanding of a study's strengths and weaknesses, as well as its contribution to practice (Duffy, 2005). Critically appraising research assesses the quality of a study in terms of its trustworthiness, relevance and usefulness, distinguishing poor research from high-quality research in order to judge its appropriateness for practice. It involves applying focused questions to determine the integrity and applicability of the research through the use of a critical appraisal tool. The use of a validated critical appraisal tool promotes validity in the appraisal process, when a number of studies need to be assessed. However, appraising the quality of studies which have used different research methods can be challenging in light of the myriad of critical assessment tools available. Williams *et al* (2020) caution that when critically appraising research it is important to differentiate between the different methodological approaches, the context within which the research took place, methods of sampling, data collection and data analysis and the role of the researcher in the process, in order to avoid applying quantitative understandings of bias to judge qualitative studies and vice versa.

The Mixed Methods Appraisal Tool (MMAT) is a validated critical appraisal tool that can be used to appraise the methodological quality of qualitative, quantitative and mixed methods studies, including randomised controlled trials, non-randomised studies, descriptive

quantitative studies and mixed methods research for a mixed studies review (Hong *et al*, 2019; Pace *et al*, 2012). The tool was first developed in 2006 (Pluye *et al*, 2009) and was updated in 2011 (Pace *et al*, 2012). It was updated again in 2018 based on findings from a literature review of critical appraisal tools, interviews with users and an e-Delphi study with international experts (Hong, 2018). The tool is well suited for use with healthcare research and is particularly suitable to appraise studies which examine complex phenomena that are context-specific (Pace *et al*, 2012). Instead of using different quality appraisal tools depending on the type of study being appraised, it was believed that a degree of consistency was achieved by using the same tool to appraise all studies included, which is a strength of this review.

All 62 studies which met the inclusion criteria for this review were appraised using the MMAT 2018 version. The tool contains two screening questions for all studies, and a further five questions relevant to each of the study designs, i.e. qualitative, quantitative and mixed methods studies. Each study was assessed against the seven screening questions, with possible answers being “Yes”, “No” or “Can’t tell”. The maximum possible score was seven “Yes” answers out of seven. Following completion of each appraisal percentages were calculated. Those studies that received seven or six “Yes” answers, scored 85% or higher and were deemed to be of good methodological quality. Those studies that received five or four “Yes” answers scored between 71% and 57% and were deemed to be of moderate methodological quality. Finally, those studies that received three or less “Yes” answers scored 43% or lower and were deemed to be of poor methodological quality. No study was excluded following the quality appraisal process, as they had all met the inclusion criteria. Appendix 12 provides four examples of completed MMAT forms. As with the data extraction process, the primary researcher completed the critical appraisal process for each included study. Two research supervisors then reviewed the completed appraisal forms. Any disagreements that arose between the reviewers were resolved through discussion and consensus. The two screening questions which were applied to all studies were:

- 1) Are there clear research question(s) or objective(s)? and
- 2) Do the collected data address the research question(s) or objective(s)?

Table 3.5 outlines the five quality appraisal questions applied to each study relevant to its design.

Table 3.5 - Critical appraisal questions applied to included studies

Qualitative studies	Quantitative descriptive studies	Quantitative non-randomised studies	Quantitative randomised studies	Mixed methods studies
Is the qualitative approach appropriate to answer the research question?	Is the sampling strategy relevant to address the research question?	Are the participants representative of the target population?	Is randomisation appropriately performed?	Is there an adequate rationale for using a mixed methods design to address the research question?
Are the qualitative data collection methods adequate to address the research question?	Is the sample representative of the target population?	Are measurements appropriate regarding both the outcome and intervention (or exposure)?	Are the groups comparable at the baseline?	Are the different components of the study (qualitative and quantitative data/ results) effectively integrated to answer the research question?
Are the findings adequately derived from the data?	Are the measurements appropriate (i.e. clear origin, or validity known, or standard instrument)?	Are there complete outcome data?	Are there complete outcome data?	Are the outputs of the integration of qualitative and quantitative components adequately interpreted?
Is the interpretation of results sufficiently substantiated by data?	Is the risk of non-response bias low (i.e. is there an acceptable response rate (60% or above)?	Are the confounders accounted for in the design and analysis?	Are outcome assessors blinded to the intervention provided?	Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?
Is there coherence between qualitative data sources, collection, analysis and interpretation?	Is the statistical analysis appropriate to answer the research question?	During the study period, is the intervention administered (or exposure occurred) as intended?	Did the participants adhere to the assigned intervention?	Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?

Table 3.6 outlines the results of the quality appraisal process. Nine studies (one mixed methods study and eight quantitative studies) were deemed to be of poor methodological quality because of a lack of clarity in relation to the potential for researcher bias, especially during the data collection and data analysis phases, or due to limited or no information regarding the recruitment strategy and implications for practice included in the publication.

Table 3.6 - Results of the quality appraisal process of all studies included in literature review

	Qualitative studies	Quantitative studies	Mixed Methods studies	Total
Good	28 (19 + 9)	1 (0 + 1)	2 (2 + 0)	31
Moderate	3 (3+0)	15 (12 +3)	4 (2 + 2)	22
Poor	0	8 (6 + 2)	1 (1 + 0)	9
Total	31 (22 + 9)	24 (18 + 6)	7 (5 + 2)	45 +17

3.4.4 Data analysis

Data analysis of the qualitative studies (n=31) was guided by the principles of thematic analysis, which Braun and Clarke (2006: p. 79) describe as “a method for identifying, analysing, and reporting patterns (themes) within data.” The quantitative studies (n=24) were summarised, while data from mixed methods studies (n=7) were analysed using both methods. The findings from all studies were then analysed using thematic analysis. Thematic analysis takes a well-structured approach to managing data and is useful to aid in identifying key features in a large data set (Nowell *et al*, 2017). Braun and Clarke’s (2006) six phases of thematic analysis was used as a guiding framework. Phase one involves familiarising oneself with the data. This was achieved through actively reading and re-reading each of the studies to become immersed in the content, noting initial findings. Phase two involves generating initial codes from the data which required revisiting the studies, reflecting on the data, searching for patterns within the data and grouping similar data together. Key findings emerging from each study were reviewed and the data coded to identify important features within it. According to Nowell *et al* (2017), coding allows the researcher to focus on the characteristics of the data promoting the development of ideas. Phase three involves collating the coded data from the studies into themes, where the codes were closely examined and linked together into potential themes. Themes are patterns occurring repeatedly within a data set that are important to the description of a phenomenon under review (Braun and Clarke, 2006). The fourth phase involves reviewing and refining the themes to ensure they form meaningful and logical patterns. This meant revisiting the original study, when necessary, to ensure the themes were forming a coherent pattern. Refinement of each theme continues during phase five. Each theme was checked against the original data for accuracy to ensure it reflected the findings. Finally, during phase six a final review was undertaken to ensure the agreed themes reflected the content of the studies, and clearly defined themes were created. Braun and Clarke’s (2006) process of thematic data analysis is conducted in a non-linear fashion, with the researcher moving forwards and backwards through the data until he/she is satisfied with the themes created. Analysis of the data in this way allows conclusions to be drawn on the common themes across the studies. Data analysis was supported by guidance from two supervisors, where there was disagreement, consensus was reached through discussion.

Siolemezi and Linceviciute (2018) caution if reviewing data from different countries and continents, it is important to consider how these differences may be relevant to other populations, and to the conclusions that may be drawn. They advise to remain focused on the review question and close to the original data. It was important to heed this advice, since the studies in this review originated from 25 different countries worldwide. However, it is also important to acknowledge that societies are more diverse now than ever before, and

that while data may have originated on one country, it is possible that the population within that country may have been diverse and inclusive of many different cultures. For this reason, when extracting and analysing data during this review, the characteristics of the research participants was a key feature during the data analysis phase.

3.5 Results

The findings from the 45 primary research studies identified following the initial literature search in October 2018 and the additional 17 studies identified following the updated search in October 2022 were collated into six key themes: 1) family needs, 2) forming a partnership relationship, 3) parents' desire to participate, 4) being present to provide care, 5) being present to provide emotional support and 6) challenges and barriers to effective implementation. The findings relating to each theme are presented below.

3.5.1 Family needs

The needs of parents and families while their child is in hospital was identified as a theme in a significant number of the studies included in this review (Hughes, 2007; Neal *et al*, 2007; Shields *et al*, 2008; Frost *et al*, 2010; Bellin *et al*, 2011; Coyne *et al*, 2013; Livesley and Long, 2013; Baird *et al*, 2015; Mortensen *et al*, 2015; Moore *et al*, 2015; Roscigno, 2016; Curtis and Northcott, 2017; Foster and Whitehead, 2017; Matziou *et al*, 2018; Foster *et al*, 2018; Khaksar *et al*, 2022; Saria *et al*, 2019; Terp *et al*, 2021).

In a mixed-method study using a survey and qualitative data, Neal *et al* (2007) evaluated parents and staff perceptions of how FCC was delivered on an infant and toddler unit in Arkansas, USA. They surveyed 38 families and found that 68% of them believed nursing care needs for both their child and themselves were being met. The main concern of the nurses (n=75) was the unit environment, for example congestion and a lack of “kid-friendly” *décor* (Neal *et al*, 2007; p. 483). The small sample size and the fact that the study took place in a single infant and toddler unit, means the findings must be viewed with caution. Nonetheless, Hughes (2007) supports this finding when all nurse respondents (n=28) in her study stated that it was important for parents to stay with their sick child in hospital, and all agreed that the parents should be cared for as well as the hospitalised child. Shields *et al* (2008) compared parents' (n=130) perceptions of their needs when their child is in hospital with the perceptions held by the healthcare professionals (n=79) in cross-sectional survey in a children's hospital in Australia, using the Needs of Parents Questionnaire. They found that staff, including nurses, doctors and allied health professionals, are aware of the needs of parents and families when a child is in hospital. However, the healthcare professional respondents believed that parents needed more support from staff than the parents believed. Shields *et al* (2008) concluded that parents are more independent than staff consider them to be, and are less likely to need help to meet their needs than the staff

believe. This study is now over a decade old, so the findings must be interpreted cautiously, especially given that the participants were all drawn from one hospital in Australia.

Mortensen *et al* (2015) examined the association between parents' symptoms of acute stress disorder and their experience of nursing care in a PICU in Denmark, where FCC was practiced. Ninety parents participated in this cross-sectional study which used two self-report questionnaires to measure parents' experience of the care and support they received from nursing staff and their level of acute stress symptoms. Thirty-four *per cent* of the mothers and 29.5% of the fathers experienced symptoms of acute stress disorder. The parents reported that they received more care and support from the nurses when their stress levels were high. Mortensen *et al* (2015) concluded that nurses must be aware of the needs of parents and provide the appropriate level of help and support for them while their child is in PICU. The small sample size limits the application of the findings to other settings. The researchers recommend that further research is needed, with a larger sample, to examine the effect of a child's admission to PICU and the care parents receive from nursing staff.

In a large children's hospital in the USA, Frost *et al* (2010) used a pre-test/post-test design to survey parents (n=39) and staff (n=76). These researchers wanted to identify parents and staff perceptions of FCC, aiming to use the findings to make changes to improve practice in an infant and toddler unit. Prior to the intervention parents reported a lack of involvement in pain assessment, lack of continuity of care and a need for improved staff interaction with parents. Parents were surveyed again after the intervention, which included the development and delivery of "a unit-wide educational programme, after which the staff developed a family-centered care framework for the unit" (Frost *et al*, 2010; p. 145). Parents reported being included in decision-making and pain assessment, feeling respected and experiencing greater satisfaction and team work in the post-test survey. Although a small survey and methodologically flawed, the findings are supported in further research. Moore *et al* (2015) claim that, if practiced well, a FCC approach will help to reduce parental stress associated with their child's hospitalisation. A cross-sectional quantitative study by Bellin *et al* (2011) which examined the practice of FCC from the perspectives of parents (n=92) and healthcare professionals (n=43) in a large urban hospital in the USA, recognised that healthcare professionals were meeting the needs of families generally, and specifically their need for ongoing communication and information about their child's treatment and progress. Healthcare professionals were respectful of parents' knowledge and expertise (Bellin *et al*, 2011). However, methodological limitations include the low response rate especially from parents, the small sample of healthcare professionals and the possibility that those who responded to the survey, both parents and healthcare professionals, may have done so because they had more positive experiences of FCC, resulting in biased responses. These limitations restrict the applicability of the findings.

Emotional and financial support for families was stated by nurses as the element of FCC most frequently implemented in a study investigating the practices and perceptions of children's nurses toward FCC in Ireland (Coyne *et al*, 2013). There was a poor response rate of 33% from the 750 nurses who were eligible to participate, which is a limitation of the study. Nonetheless, these findings were supported in a qualitative study by Foster and Whitehead (2017) carried out in New Zealand, which included data from both parents (n=91) and members of the multidisciplinary team (n=66). The importance of meeting the family's needs in terms of practical needs such as meals, showering and sleeping facilities, and psychosocial support such as the services of the minister and social work team were recognised. The family's needs were described more by parents than by staff in this study, while the staff participating appeared to place greater importance on meeting the needs of the child than those of the family. In a study in Brazil (de Macedo *et al*, 2017) found that nurses believed families need psychological support to help them through their experience of being in hospital with their sick child, regardless of the child's illness. It was identified that active listening and engaging with parents promotes an enhanced understanding of family needs and values in a descriptive qualitative study in the USA (Rosignano, 2016). This study examined the perceptions of how nurses can provide caring support for parents while their child is in hospital and included interviews with 29 parents from 25 families. However the participants in this study were limited to parents of a child with a traumatic brain injury so the findings must be interpreted with care. Nonetheless, this finding is supported by Uhl *et al* (2013) who found effective communication with the healthcare team enhanced parental engagement, and that applying FCC to practice helps to reduce parental stress. Seliner *et al* (2016) also supported this finding when they found that respectful, open communication and participation in discussions with the healthcare professionals caring for their child helped parents to overcome their worries and anxieties.

Practices and policies prioritise the comfort and convenience of staff above those of children and families was a key finding in a 12-month prospective ethnographic study in a tertiary referral hospital in the USA (Macdonald *et al*, 2012). The researchers used participant observation and interviews to elicit the experiences of 18 families of children in PICU, and found that children were viewed more as a patient than as a child and parents felt they were viewed more as a visitor than a parent. As with all qualitative research the findings are not generalisable beyond the study setting. However, this finding was supported by Baird *et al* (2015) in a grounded theory study conducted in a PICU in a large teaching hospital in Western USA where data were collected by observation and through interviews with seven parents and 12 nurses. These researchers recognised that the existence of rules within the PICU promoted the notion of parents as visitors with restricted access. They concluded that such rules were not conducive to the delivery of care that was reflective of the needs of the family. The nurse participants in this study were all female and only one was not

white Caucasian. Furthermore, the study was carried out in a single PICU. In addition, since both these studies (Macdonald *et al*, 2012; Baird *et al*, 2015) were carried out in the PICU setting, this finding cannot be applied to the care of children in a general children's ward setting. However, Arabiat *et al* (2018) in a study based in a paediatric unit in Western Australia, supported these findings reporting that one of the three themes contributing to FCC is the provision of care to the whole family.

Rasmussen *et al* (2017) examined the stories told by children during family interviews following the child's stay in hospital in New Zealand. In this qualitative narrative study they found that the child and parent experience may be different. Many of the children viewed their stay in hospital in a positive way, citing the friendly people they met and having familiar things and people from home around them as reasons for a positive experience. However, this study found that parents may not always concur with the child's experience. Parents reported that "fitting in and playing along was important" (Rasmussen *et al*, 2017: p. 449) and sometimes overshadowed their personal needs. Only nine interviews with children were included in this study, so the findings must be viewed with caution. These researchers argue that a family-centred approach to care is well established within children's healthcare internationally and children are central to this approach to care, however the role of the child within FCC is not recognised. They are critical of the fact that frequently only the parents' views of the hospital experience are sought and that children are largely excluded from the research process, thus failing to identify the needs of hospitalised children.

More recently, Foster *et al* (2018) examined the relationship between staff and parents' perceptions of parents' needs during a hospital admission in a secondary children's hospital in Western Australia. Using a cross-sectional descriptive design, 46 parents and 17 staff completed the Needs of Parents' Questionnaire. Parents rated family needs as more important and more likely to be met than the staff rated them. Parents reported that the need to be trusted to care for their child in hospital, and to be informed about their child's condition, were their most important needs. They also believed these were the most met needs, which was consistent with other similar studies (Foster and Whitehead, 2017b; Shields *et al.*, 2008). The use of a convenience sampling method and a small sample size are limitations of the study.

In Iran Khaksar *et al* (2022) examined the effect of implementing an educational programme for fathers of hospitalised children on improving FCC and the stress experienced by their mothers in a randomised clinical trial. Forty mothers and fathers were selected and randomly assigned to a control and an intervention group, 20 in each group. Fathers in the intervention group received a 90-minute face-to-face training session about their roles while their child was in hospital, including ways to support the mother and child. The control group received routine care. Mothers from both groups completed a Stress Response Inventory

questionnaire on admission and again seven days later. Mothers from the intervention group reported significantly lower levels of stress than mothers in the control group who received routine care, and continued to report high levels of stress throughout the seven days of the study (Khaksar *et al*, 2022). The researchers concluded that educating and supporting fathers to act in a supportive role for mothers of hospitalised children can reduce their stress levels. Other supports which the family may have received, individual family coping styles and other stressful situations which may have been present, were not recognised and may have impacted the results.

Using a descriptive qualitative design Saria *et al* (2019) interviewed nurses (n=14) and parents (n=24) of critically ill children in the burns and ICU units of a tertiary teaching hospital in Tanzania. They sought to describe nurses and parents perceptions of the needs of parents when caring for their critically ill child in hospital. Data were analysed using content analysis. Two themes were identified: “engaging parents in the care of their children” and “receiving psychosocial support”. Parents reported that complete and timely information from the nurses on their child's progress was very important to them, but they described feeling frustrated because they did not receive adequate information. While the nurses appeared to be aware of the importance of providing adequate information to parents, they explained that a shortage of staff was an inhibiting factor. Nurses reported that parental participation in care helped to relieve their workload (Saria *et al*, 2019). The interviews were held in Kiswahili and transcripts were translated into English. Data were analysed from the English version, the authors recognised that there is a risk that some information may have been lost in translation. In addition, the study was conducted in a developing country, so the findings must be considered in that context.

Likewise, Terp *et al* (2021) found that timely information was key to parental satisfaction in a qualitative descriptive study conducted in two PICUs in Sweden using the Swedish version of the **EM**powerment of **PA**rents in **THE** Intensive **C**are (Empathic)-30 questionnaire, a validated tool which measures parents' satisfaction with their child's care in PICU. Seventy questionnaires, which were completed on discharge from the unit, were received. The questionnaires included five open questions which required free-text answers, the data were analysed using thematic analysis. Parents felt supported when they received timely information about their child's condition, and described feeling a sense of security when they were well informed. They expressed feeling confident and secure when they knew the team and the team knew them, saying that frequent changes in staff caring for their child made them feel insecure (Terp *et al*, 2021). Limitations include that the questionnaire was translated to Swedish for use in this study and an additional question was added. Validity of the amended questionnaire was not confirmed.

3.5.2 Forming a partnership relationship

It is well documented that the formation of a respectful and trusting partnership relationship between the hospitalised child, his/her parents and the nurse is the foundation upon which FCC is built (Casey and Mobbs, 1988; Coyne, 1996; Franck and Callery, 2004; Shields, 2010; Mikkelsen and Frederiksen, 2011; Kuo *et al*, 2012; Dennis *et al*, 2016; Foster *et al*, 2016; Smith *et al*, 2015; Tallon *et al*, 2015; Banerjee *et al*, 2018). Consequently it is not surprising that partnership formation was identified as a key aspect of FCC in many of the studies included in this review (Hughes, 2007; Neal *et al*, 2007; Avis and Reardon, 2008; Ames *et al*, 2011; MacKay and Gregory, 2011; Coyne, 2013; Moore *et al*, 2015; Foster and Whitehead, 2017; Arabiat *et al*, 2018; Matziou *et al*, 2018; Murrell *et al*, 2018; Phiri *et al*, 2019; Ohene *et al*, 2020; Fisk *et al*, 2022).

MacKay and Gregory (2011) interviewed 20 nurses working in a children's oncology unit in Western Canada seeking to better understand their experiences of FCC and how they implemented it in their daily practice. The development of a therapeutic relationship with the child and family was identified as important and enhanced the nurses' ability to deliver individualised care to the child and family. However, children and their parents were not included in this study. Developing a relationship of trust with the healthcare team was recognised by Ames *et al* (2011). In a study set in the PICU of a tertiary care hospital also in Canada, they sought to explore parents' (n=7) perceptions of their role when their child was cared for in PICU. They found that a key dimension to the parental role is that of forming a partnership of trust with the healthcare team by sharing their parental expertise and keeping up-to-date with their child's progress. This study used a qualitative interpretive design and in-depth semi-structured interviews to collect data from seven parents (five mothers and two fathers) who had a child in PICU (Ames *et al*, 2011). This research is limited by its small sample size, further research to examine how emergency admission versus planned admission to PICU impacts on the parental role is needed, to confirm the findings. Nonetheless, these findings were supported by Foster and Whitehead (2017) in a study carried out in New Zealand which explored parents' (n=91) and multidisciplinary staff (n=66) perceptions of FCC. This paper presented the qualitative findings of the original study, which took a mixed methods approach. The importance of the time spent by nurses and doctors developing a relationship with parents was identified, describing this relationship as "the basis for providing FCC" (Foster and Whitehead, 2017; p. 494). These findings must be viewed in the context within which the data were collected, in one Paediatric High Dependency Unit (PHDU) in New Zealand, which did not admit children who required full respiratory support, hence the findings may not represent FCC within other critical care areas. In addition, parents completed the questionnaires while their child was still an in-patient in the unit, which may have contributed to biased responses due to parental

concern about any adverse effect a negative response may have had on their child's care. Another limitation of this study, as identified by the authors, was that most staff and parents were of European origin, and did not represent a wider cultural background. Further research is needed to deliver care that is culturally appropriate and should include the child's perceptions of their care needs while in hospital, in order to inform FCC policy and practice (Foster and Whitehead, 2017).

Uhl *et al* (2013) carried out a mixed methods study in the USA which aimed to describe parents' care experiences during their child's hospitalisation and were critical of how parents felt when their child was in hospital. These researchers collected data through focus group interviews with parents of hospitalised infants and children (n=9) by survey (n=134). The parents stated that they sometimes felt obliged to participate in the care of their child, and at other times they felt a nuisance. Rather than feeling they were a member of the team, the parents described feeling under pressure to relinquish their position of primary carer and become a more passive participant in their child's care. This study included only nine parents and was conducted in one site, also the response rate to the survey was only 10.2%, which restrict the application of the findings to other settings. Nevertheless, when de Macedo *et al* (2017) explored nurses' understanding of family presence with their child in hospital, they reported that nurses must develop a relationship of mutual respect and trust in order to meet the needs of the family and deliver optimum FCC.

In a cross-sectional mixed methods study conducted in Australia, parents (n=48) completed a seven-item FCC Scale questionnaire, measuring their experiences of nursing care associated with the core elements of FCC (Arabiati *et al*, 2018). Participants also responded in free text to an open-ended question about what FCC means to them. The parents expressed a clear understanding of partnership-in-care, describing themselves as partners with the healthcare team as well as care recipients. Furthermore, they viewed family inclusion in care activities and decision-making as contributing to a feeling of being valued as a team member. Both Okunola *et al* (2017) and Murrell *et al* (2018) support this finding. Okunola *et al* (2017) reported that both parents and nurses believed that treating parents as a valued member of the team caring for the hospitalised child was an important element of FCC. Murrell *et al* (2018) found that parents placed significant value on the development of a strong nurse-parent partnership, which was associated with respect and information sharing. This study was conducted in a children's hospital in Texas and included interview data from parents of children with spinal muscular atrophy only, which limits the applicability of the findings. In a study of Greek nurses' perceptions of FCC and how they applied the model to their everyday practice, it was reported that nurses working in co-operation with parents was the most important element of FCC (Matziou *et al*, 2018). However, the survey questionnaire used in the study was based on the FCC Questionnaire Revised (FCCQ-R)

which was still under development, the authors acknowledged that some of the questions required refinement (Matziou *et al*, 2018).

The concept of a partnership relationship was challenged in research undertaken by Phiri *et al* (2019) in Malawi, who explored nurses' experiences of applying FCC to the care of children and their families in a tertiary hospital using a descriptive qualitative design. Fourteen nurses working on the children's wards were interviewed, using a semi-structured interview guide based on the principles of patient- and FCC, as described by the Institute of Patient- and Family-Centered Care (Johnson and Abraham, 2012). Phiri *et al* (2019) found that nurses applied the core concepts of FCC in their daily practice, but they controlled the extent to which families were allowed to take on nursing care activities when caring for their child. Parents were involved in delivering care as instructed by the nurses, but not in planning care. The nurses stated that family involvement in care helped to reduce their workload, as there was a shortage of nurses, but that family involvement "must be regulated" in order to ensure that the care delivered by parents is safe (Phiri *et al*, 2019: p. 236). The nurses in this study reported that they controlled parental involvement by not including them in care planning, stating that most parents "did not understand the planning process" (Phiri *et al*, 2019; p. 234). This power dynamic is in direct contrast to the development of a true partnership relationship, which is a fundamental principle of FCC. These findings are specific to the hospital where the data were gathered in Malawi, which is a developing country with more limited resources than in Western countries. Furthermore, only nurses were included in the study, and parents may have offered a different perspective, which would have added to the study in terms of the knowledge generated and the applicability of the findings.

In another study by Phiri *et al* (2020) in Malawi, parents' perceptions of their participation in the care of their hospitalised child was explored using a descriptive qualitative approach. Twenty parents of hospitalised children were interviewed, the data were analysed using thematic analysis. Most parents stated that the nurses delegated tasks to them without any discussion, and that the nurses did not teach them how to care for their child in hospital. As a result they felt inadequately prepared to carry out these tasks. The authors concluded that parents receive inadequate information from nurses, and that there is inadequate role negotiation with parents when they are in hospital with their child, advising that nurses should develop a mutual partnership with parents if their participation is to be effective (Phiri *et al*, 2020). These findings must be viewed in the cultural context where the data originated, where FCC may be seen as a Western concept.

Nonetheless, similar findings have been reported in research conducted in Western countries. Terp *et al* (2021) in the USA found that incomplete partnership formation was a dominant theme in their research. They identified that there was a potential to further

develop a partnership relationship in areas such as parents being actively involved in clinical decision-making about the care and treatment for their child, and improved communication that could recognise parents' needs in PICU. Likewise, McCann (2018), also in the USA, asserted that children's nurses assign the non-medical cares to the parents without negotiation about what they would like or are able to do. She examined the effectiveness of using a Negotiated Care Tool (NCT) to ascertain the extent to which parents wish to participate in care. In an experimental study McCann (2018) used a convenience sampling method, randomly assigning 32 parents to the experimental group and 32 to the control group. She found there were significant improvements in nurses' communication and negotiation with parents when they used the NCT, claiming that using it would improve parent-nurse relationships.

Ohene *et al* (2020) explored the perceptions of FCC among healthcare professionals caring for hospitalised children, using a grounded theory approach. They interviewed 21 nurses and three orthopaedic surgeons in two major hospitals in Ghana. Family involvement in care was identified as a key element of FCC, the degree of their involvement appeared to depend on their relationship with the nurses. Most nurse participants believed parents helped the nurses with basic nursing care, and keeping children calm during painful procedures. All participants reported that parents provided "a helping hand" which was considered necessary to supplement the shortage of nursing staff (Ohene *et al*, 2020; p. e52). Only nurses and orthopaedic surgeons were included in this study, it is likely that other healthcare professionals may have different understandings of FCC. As with all qualitative research the findings are context specific, which is especially significant in this study, as the Ghanaian culture and the limited healthcare resources available are restrictions to the usefulness of the findings in Western settings. While similarities exist in healthcare professionals' understanding of FCC, differences in practice across America, Australia and Turkey have been reported previously (Feeg *et al*, 2016).

A team of Turkish researchers who sought to determine the attitudes and behaviours of nurses working in the state children's hospital, surveyed 304 nurses working in paediatric clinics using a quantitative descriptive design and the Parent Participation Attitude Scale (Kurtulus *et al*, 2018). They found that nurses working in the PICU had the lowest score and nurses working in internal medicine clinics and the NICU had the highest score. The authors recommended that PICU nurses should promote active involvement of the family in the child's care in hospital and work in partnership with them. The sample strategy was not well explained and the response rate was not addressed by the authors. For these reasons the methodological quality of this research is only moderate. Additionally the study was based in a single hospital in Turkey, hence the findings must be viewed with some caution.

Abdelkader *et al* (2016) examined parental contribution to care of hospitalised children in four major hospitals in Jordan using the Index of Parent Participation/Hospitalized Child scale, and found that parents whose child was hospitalised previously participated more in the care of their child. They also found that participation in care by parents of children aged three to six years old was significantly higher than that of parents of younger or older children. They contend that parents' participation in care may reflect a cultural expectation, concluding that a partnership between parents and nurses must be developed to ensure parents are involved in their child's care activities and decision-making. They also claim that parental involvement in care must be initiated and supported by nurses (Abdelkader *et al*, 2016). A convenience sampling strategy was used and the response rate was not stated, so it is not possible to state if the sample was representative of the target population.

3.5.3 Parents' desire to participate in care

There is evidence from many of the studies that parents of hospitalised children want to actively participate in their care (Coyne and Cowley, 2007; Ames *et al*, 2011; Coyne, 2013; Higham and Davies, 2013; Romaniuk *et al*, 2014; Rostami *et al*, 2015a; Abdelkader *et al*, 2016; Roscigno, 2016; Schalkers *et al*, 2016; Curtis and Northcott, 2017; de Macedo *et al*, 2017; Okunola *et al*, 2017; Saria *et al*, 2019; Vasey *et al*, 2019; North *et al*, 2020; Ohene *et al*, 2020; Phiri *et al*, 2020) albeit to varying degrees. Generally parents were reluctant to perform more technical or clinical care procedures that could cause discomfort or pain, and where there was a risk of causing harm to the child (Coyne and Cowley, 2007; Saria *et al*, 2019). In an American study, Roscigno (2016) used descriptive phenomenology to explore parents' expectations of caring encounters with nurses during the early acute stage of their child's severe traumatic brain injury. Although a small sample from a distinct cohort of participants, the parents considered that nurses who supported them to be involved in their child's care in hospital were caring nurses, and they expressed greater satisfaction with nursing care. Similarly, a quasi-experimental study in Thailand (Kuntaros *et al*, 2007) included 32 mothers, 16 in the control group receiving usual nursing care, and 16 in the experimental group receiving a FCC approach. The researchers identified that the mother's involvement in her child's personal care and satisfaction with nursing care were significantly increased in the experimental group.

Coyne (2013) found that parents were allowed to take on more complex care as they became more competent and nursing staff developed confidence in their abilities, especially when the child had a chronic condition. Coyne's (2013) study took a grounded theory approach to explore parents' (n=18), children (n=18) and nurses' (n=18) views and experiences of FCC in an attempt to understand how roles are negotiated. Data were collected in two children's hospitals and one children's ward in a large general hospital in Ireland and analysed using constant comparison techniques. Coyne (2013) found that

children were willing to have their parents learn and take on care procedures if the procedures were needed at home following discharge, even if they were complex and caused discomfort. However, a dependence on parents to be present and caring for their sick child in hospital placed added pressure on parents and families, often leading to conflict and increased stress for parents (Coyne, 2013). Lee and Lau (2013) had similar findings when they interviewed 15 mothers of hospitalised children in two hospitals in China using an interpretive phenomenological approach and thematic analysis. They found that mothers wanted to participate in the care of their child, and expressed concerns about their child being uncared for by the busy healthcare professionals. The small sample size and the fact that only mothers were included as participants are identified as study limitations. Nonetheless, this finding is further supported by Higham and Davies (2013) in an ethnographic study including observation and interviews with 12 fathers of hospitalised children in a children's hospital in the south of England. The fathers in this study wanted to be with their child and participate in caring for them. They also wanted to participate in clinical decision-making about healthcare choices for their child.

Curtis and Northcott (2017) reported similar findings in a focused ethnographic study in the UK, where data were collected through observation and interviews with children (n=17), parents/carers (n=60) and nursing/support staff (n=60) over a 10-month period. Many of the children assumed that their parents “should – and would – provide basic care while they were in hospital” (Curtis and Northcott, 2017; p. 1589). These researchers also reported that the majority of parents wanted to provide more, rather than less, care for their child. This study was conducted in one children's hospital in the north of England and minority ethnic families were not included, which results in these families being under-represented. Despite these limitations, Hill *et al* (2018b) also support this finding in a qualitative descriptive study using secondary analysis from a longitudinal study, examining parents' perception of how the physical and cultural environment of a PICU impacted on the implementation of FCC. They discovered that parents were keen to participate in “more complex aspects of parenting such as involvement in treatment, decision-making and care planning” during the prolonged hospitalisation of their critically ill child in the PICU (Hill *et al*, 2018b, p. 91). The small sample and the fact that the participants were cared for in the same PICU were identified as limitations of the study.

Cimke and Mucuk (2017) examined mothers' participation in care and their satisfaction with care in a quantitative descriptive study in Turkey. The mothers (n=285) completed a Paediatric Quality of Life Inventory Health Care Satisfaction Scale and Family-Centred Care Scale. There was a strong positive association between the mothers' quality of life and Family-Centred Care Scale scores. The mothers' participation in the care of their hospitalised child and knowing what was happening with their child resulted in greater

satisfaction with healthcare. However, the study was conducted in a single centre in Turkey. Notwithstanding this limitation, Okunola *et al* (2017) supported this finding in a study carried out in two children's hospitals in Nigeria using a descriptive design to examine parents (n=323) and nurses (n=176) understanding of the FCC nursing care behaviours they considered most and least important. A modified version of the Family-Centered Care Scale was used to collect data, and descriptive statistics used to analyse the data. Parents and nurses agreed that parents participating actively in their child's care was an important element of family-centred nursing. This study was conducted in Nigeria which is culturally very different to the settings of most of the studies included in this review, it is also a resource limited country which may have implications for nurse staffing and the nursing workload. Furthermore, children were not included as participants.

Nevertheless, studies carried out in the USA by Uhl *et al* (2013), in Turkey by Boztepe and Kerimoğlu Yıldız (2017) and in Sweden by Terp *et al* (2021) support this finding. In these studies, parents described having the opportunity to participate in care and decision-making as important to them. Parents expressed appreciation at being allowed and encouraged to carry out caring activities for their hospitalised child, reporting that it made them feel important and valued (Terp *et al*, 2021). It is also important to understand that not all parents want to participate in caring for their hospitalised child to the same extent (Uhl *et al*, 2013). In a study by Saria *et al* (2019) in Tanzania some parents expressed that they were uncomfortable being involved in their child's care because they were afraid they might hurt him/her. Saria *et al* (2019) concluded that nurses should not assume that parents want to be involved in their child's care without discussing it with them. These findings confirm that parents want to actively participate in their hospitalised child's care. They also provide some evidence that parental involvement in care results in greater satisfaction with care which is beneficial for the child, the parents and the healthcare organisation (Uhl *et al*, 2013; Mortensen *et al*, 2015; Rostami *et al*, 2015a; Boztepe and Kerimoğlu Yıldız, 2017; Cimke and Mucuk, 2017; Terp *et al*, 2021).

Schalkers *et al* (2016) explored healthcare professionals' (n=32) views on child participation in hospital care in the Netherlands through semi-structured interviews. The participants reported that high levels of participation in a child's own care was possible, especially in fundamental care procedures, while participation in more complex care such as medical decision-making, requires restrictions depending on the child's age, condition and the decision to be made. Chronically ill children were often given more responsibility in decision-making about their own treatment, than acutely ill children (Schalkers *et al*, 2016). However, only the views of healthcare professionals were elicited. The views of children and their parents may have given a different perspective on this issue, hence the findings must be considered with caution.

A cross-sectional study by Romaniuk *et al* (2014) conducted in Canada measured the actual and desired level of parental participation in the care of their hospitalised child, and compared the results. This study included data from 191 parents, mostly mothers, who completed two questionnaires. The results indicated that the majority of parents wanted to increase participation in their child's care, but may be discouraged from doing so due to a lack of information and negotiation with the nurses. However, other parents considered participation in care as stressful and did not wish to participate any further. These researchers concluded that supporting increased parental participation in care may enhance families' experience of hospitalisation and their satisfaction with care (Romaniuk *et al*, 2014). Limitations of the study include the use of convenience sampling methods and the majority of the responses came from mothers. Nonetheless, the questionnaires used had proven reliability and validity which is a strength of the study. In addition, the findings have been supported in other research included in this review (Ames *et al*, 2011; Rostami *et al*, 2015a; Phiri *et al*, 2019; Gangodage Done *et al*, 2020). Rostami *et al* (2015a) reported that applying FCC to the care of hospitalised children and their families can increase parental satisfaction. This quasi-experimental study conducted in a children's ward in Iran included the parents of 70 hospitalised children under three years of age. Two groups were established, a control group who received routine care (n=35) and an experimental group who received FCC (n=35). Data were collected using the Family Satisfaction Questionnaire which was developed by the Institute of Patient and Family Centered Care (IPFCC) and analysed using Statistical Package for the Social Sciences (SPSS) software. All parents in the experimental group reported a high satisfaction level with the care they received. Rostami *et al* (2015a) contend that FCC may lead to increased quality of care and that education, and that FCC should be included in all children's nursing educational programmes. A single site was used for data gathering and a convenient sampling method applied which limits the application of the findings.

More recently in a study by Vasey *et al* (2019) exploring parental involvement in their child's pain management in two District General Hospitals in the North of England, it was reported that although FCC was the model of care applied in these hospitals there was limited evidence that it was being implemented. While the nurses intended to involve parents in the care and management of their child's pain, they did not always do so in practice. Using an ethnographical approach, data were collected through non-participant observation of 30 children receiving care, and follow up semi-structured interviews with their parents (n=30) and nurses (n=14). Even when they were not supported by nurses, parents continued to advocate for effective pain management for their child. Variations in parental involvement were identified depending on the perceptions of the nurse caring for the child (Vasey *et al*, 2019). The authors suggest that a larger sample in a variety of settings may enhance the findings and their usefulness in another setting.

3.5.4 Being present to provide care

A number of studies discussed the importance of parents being present to provide care in the context of helping busy nurses (Hughes, 2007; Coyne and Cowley, 2007; Avis and Reardon, 2008; Coyne, 2013; Lee and Lau, 2013; Livesley and Long, 2013; Curtis and Northcott, 2017; Phiri *et al*, 2019; Prasopkittikun *et al*, 2019; Saria *et al*, 2019; Ohene *et al*, 2020).

Hughes (2007) carried out a descriptive survey of children's nurses (n=28) and parents (n=43) of children in a children's unit in a regional general hospital in Ireland using two self-designed questionnaires. She found that 35% of the parents felt they must stay with their child because the nurses were too busy to adequately care for them. Limitations acknowledged by the author include that all the parents were English speaking and that the self-designed questionnaire needed further development. Furthermore, children were not included in this study. Despite these limitations Coyne and Cowley (2007) had similar findings. Parents described "feeling compelled" to be present with their child in hospital as they lacked confidence in the nurses' ability to care for their child (Coyne and Cowley, 2007; p. 896). Avis and Reardon (2008) concurred with this finding in their small exploratory study which was carried out in the UK. They interviewed 12 parents of children with additional needs in order to explore their views on how their child had been cared for by nurses in hospital. They found that parents believed their presence and involvement in care was expected rather than negotiated, and that they were unable to leave the child's side. Although the sample size was small, and the study was carried out more than a decade ago, this finding was borne out later in Coyne's study (2013) which found that parents considered the nurses were too busy to be available for their child when needed, hence their presence and help was essential. Similarly, de Macedo *et al* (2017; p.908) also found that families help nurses "especially considering staff shortage."

In a study in China by Lee and Lau (2013; p. 1813) using interpretive phenomenology, parental presence at the bedside was referred to as "constant vigilance" and a source of stress and anxiety for parents who were concerned that their child may not be cared for adequately by busy healthcare professionals. Fifteen mothers were interviewed in two children's units in two hospitals in Hong Kong. The exclusion of fathers and the small sample size limit the usefulness of the findings. Nonetheless, parental presence with the hospitalised child was expected by the nurses and considered an obligation by the parents in studies by Romaniuk *et al* (2014) and Feeg *et al* (2016) in Canada and the USA respectively. In addition, parents of children being cared for in single rooms felt greater pressure to stay with their child because parents believed the nurses visited the room less frequently, and therefore did not monitor their child as much as they would in a shared room (Curtis and Northcott, 2017). A mixed methods study by Seliner *et al* (2016) conducted in

Switzerland used interviews (n=26) and questionnaires (n=117) to collect data from parents of hospitalised children with a profound intellectual and/or motor disability. The researchers used four standardised questionnaires to measure impact on parental burden of care, health related quality of life and satisfaction with FCC. Seliner *et al* (2016; p. 153) found that parents “bear a particularly heavy burden of care”, they worry about their child's safety and feel responsible for their child's care and well-being in hospital. All the parents in this study had a child with a profound disability in hospital, their experience is likely to be significantly different to parents of children without such a disability, which is recognised as a limitation of the study. More recently in studies in developing countries by Phiri *et al* (2019) in Malawi, Prasopkittikun *et al* (2019) in Thailand, Saria *et al* (2019) in Tanzania and by Ohene *et al* (2020) in Ghana, the authors reported that parents' presence and involvement in care was seen as helpful, and often necessary to relieve the nurses' busy workload, as there was a perceived shortage of nursing staff. It is known that there are much greater nurse to patient ratios in developed countries than in resource-limited countries (Shields *et al*, 2018). Nevertheless, these findings mirror the findings from Western countries, where parents feel compelled to stay with their child in hospital because they perceive the nurses as being too busy (Hughes, 2007; Coyne and Cowley, 2007; Avis and Reardon, 2008; Coyne, 2013; Lee and Lau, 2013; Livesley and Long, 2013; Curtis and Northcott, 2017; Phiri *et al*, 2019; Prasopkittikun *et al*, 2019; Saria *et al*, 2019; Ohene *et al*, 2020).

Despite these studies being from different cultural settings, parents feeling an obligation to be present with their child in hospital to provide care because the nurses are too busy appears to be consistent internationally. This is concerning in light of the findings from a study by Livesley and Long (2013) which identified that children in hospital relied on their parents or another adult to ensure their voice was heard, and that they felt abandoned in the absence of a supportive adult. Livesley and Long (2013) used critical ethnography to develop insights into children's experiences of being in hospital. They collected data from 15 children aged five to 15 years over a six-month period through observation, interview, play and craft activities, and used constant comparative methods to analyse the data. Children whose parents were not with them in hospital were more likely to have their needs overlooked and receive only minimum care interventions (Livesley and Long; 2013). Since this study contained a small sample size (n=15) and was conducted in a single unit in a children's hospital in England the findings may need to be confirmed in a larger study.

3.5.5 Being present to provide emotional support

The importance of parents being present with their sick child in hospital was described in ten studies in the context of them being a source of comfort, emotional support and reassurance for them (Coyne and Cowley, 2007; Hughes, 2007; Ames *et al*, 2011; Coyne,

2013; Higham and Davis, 2013; Romaniuk *et al*, 2014; de Macedo *et al*, 2017; Foster and Whitehead, 2017; North *et al*, 2020; Ohene *et al*, 2020; Fisk *et al*, 2022).

Coyne and Cowley (2007) used a grounded theory approach to explore the views and experiences of hospitalised children (n=11), their parents (n=10) and nurses (n=12) on participation in care. They collected data through interviews and participant observation in four children's wards in two hospitals in England. This study identified that the hospital experience can be boring for children and that the parents' presence can help to alleviate the boredom, through chatting, reading and playing with their child. The majority of the parents were white, British mothers, the views of fathers were not elicited and families from a multi-cultural background were not included. Notwithstanding these limitations, other studies have also described parental presence as necessary to provide emotional support, security and comfort for the child in hospital (Coyne, 2013), especially when the child is cared for in a single room (Curtis and Northcott, 2017). Boztepe and Kerimoğlu Yıldız (2017) conducted a qualitative study exploring nurses' views of FCC and their perceptions of the barriers associated with its implementation in a children's hospital in Turkey. They reported that the nurses believed parents know their children best and that children felt comfortable and safe in hospital when their parents were present, claiming that parental presence close to the child was important in order to provide continuity of family life for the child. These findings should be viewed within the context of a small sample of 18 nurses at one hospital in Turkey, and the recognised limitation by the authors that there is a nationwide lack of awareness of FCC in Turkey (Boztepe and Kerimoğlu Yıldız, 2017). Similarly, de Macedo *et al* (2017) conducted a qualitative study in a children's unit in a university hospital in Rio de Janeiro, Brazil, where 14 nurses took part in unstructured group interviews. Thematic analysis was used to analyse the data. All the nurses believed that family presence provides emotional support to the child in hospital (de Macedo *et al*, 2017). The small sample size and the fact that they were all drawn from a single unit, make the findings difficult to transfer to other settings.

Additionally, in more recent studies by North *et al* (2020), Ohene *et al*, (2020) and Fisk *et al* (2022) it was recognised that parents provided care, comfort and emotional support for their child in hospital. North *et al* (2020) used a qualitative case study design to examine nursing practices which facilitated family involvement in care in rural South Africa. Data were collected through observation and focus group interviews involving 20 nurses and 22 mother and child pairs. There was an expectation that the mother (or grandmother) would stay with the child to provide emotional support and care for them in hospital (North *et al*, 2020). All the children were cared for in a full-sized adult bed, which allowed the mother to co-sleep with the child, which is a culturally acceptable practice in South Africa, and may not be considered appropriate in Western societies. Furthermore, the mother was expected

to stay with her child, without consideration for other commitments she may have, either at home or at work (North *et al*, 2020). This study is specific to the hospital where data were gathered in South African, hence the findings must be viewed with caution. Nevertheless, Fisk *et al* (2022) had similar findings in a qualitative descriptive study exploring the experience of parents' in the Paediatric Cardiac Intensive Care Unit (PCICU) in a large tertiary hospital in the USA. Eleven parents from seven families were interviewed. Parents described their roles as providing emotional support and care, and advocating for their child while he/she was in PCICU. This was a very small study with only 11 participants in one hospital in the USA, so the findings must be viewed with caution.

3.5.6 Challenges and barriers to effective implementation

Many studies have reported the challenges and barriers experienced when attempting to effectively implement FCC in practice (Avis and Reardon, 2008; MacKay and Gregory, 2011; Coyne, 2013; Coyne *et al*, 2013; Moore *et al*, 2015; Rostami *et al*, 2015b; Vasli *et al*, 2015; Feeg *et al*, 2016; Alabdulaziz *et al*, 2017; Boztepe and Kerimoğlu Yıldız, 2017; Evans, 2017; Dall'Oglio *et al*, 2018; Segantini Felipin *et al*, 2018; Farokhzadian *et al*, 2020; Gangodage Done *et al*, 2020).

A lack of understanding and knowledge of the family's culture and values were recognised as barriers when attempting to implement FCC by MacKay and Gregory (2011) in a small qualitative study in Western Canada. The purposeful convenience sampling method used to recruit the 20 nurse participants in this study may have led to biased responses and hence the findings must be interpreted with care. Notwithstanding these limitations, MacKay and Gregory's (2011) finding was substantiated by Rostami *et al* (2015b) when they examined nurses attitudes towards parents participating in their child's care in hospital. They conducted an experimental study using a random-sampling method and gathered data using a questionnaire from 200 nurses working on children's units in four university hospitals in Iran. The nurses completed the questionnaires before, immediately after and three months after an "educational intervention concerning family-centered care" (Rostami *et al*, 2015b; p. 1262). They found that there was a significant increase in the nurses' attitude to FCC in the intervention group immediately after the intervention and that this change of attitude was sustained three months after the intervention. No such change of attitude was observed in the control group. These researchers concluded that a lack of knowledge about FCC is a barrier to its effective implementation, and the provision of educational workshops about FCC positively changes children's nurses' knowledge and attitudes (Rostami *et al*, 2015b). However, this research must be viewed with some caution as there were some methodological flaws, such as the response rate not being addressed in the article. Furthermore, the cultural setting of Tehran is significantly different from the Western world. Likewise, an ethnographic study by Vasli *et al* (2015) examining the culture of FCC in a

PICU in Iran, identified that the prevailing atmosphere in the unit was paternalistic. There was a significant gap in the staff's knowledge of FCC and what was practiced within the unit, furthermore there were no facilities for parents to stay by the bedside with their sick child. These findings could be ascribed to the cultural differences that exist between Iran and the Western world from which most of the research included in this review originates. Additionally, Segantini Felipin *et al* (2018) investigated nurses' perceptions of FCC in a NICU and PICU in Brazil. Although a small sample size (n=19), the findings revealed that a lack of understanding of what constitutes FCC impeded its implementation. These authors cited organisational and training obstacles as reasons for this gap in knowledge. As this study was conducted in Brazil, it may have implications for cultural differences with Western societies. Dall'Oglio *et al* (2018) in a cross-sectional study undertaken in Italy using the Italian version of the FCCQ-R also recognised that a lack of knowledge and skills about FCC were barriers to its effective implementation. The participants (n=469) were all healthcare professionals working in in-patient clinical areas in a large teaching hospital in Italy. The data were analysed using descriptive statistics. Limitations of the study included a lower than desired response rate and a failure to conduct psychometric validation of the tool used to collect data.

Both Farokhzadian *et al* (2020) and Gangodage Done *et al* (2020) also support this lack of knowledge and understanding as a barrier to effective FCC in practice. Farokhzadian *et al* (2020) conducted a cross-sectional study in which the participants, nurses (n=60) and mothers (n=82) whose children were being cared for in PICU or the paediatric oncology unit in a university hospital in Iran, were asked to complete a two-part questionnaire to assess their perceptions of the barriers to FCC. These researchers found that nurses' lack of knowledge and poor communication skills were reported by both mothers and nurses as significant barriers to effective FCC (Farokhzadian *et al*, 2020). The questionnaire used to collect data was newly developed by the researchers, its validity was not well established. Furthermore only mothers and nurses were included in the sample, a wider participant group, including other family members and healthcare professionals, is likely to reveal different insights and add to the validity of the findings. Likewise, Gangodage Done *et al* (2020) had similar findings in a mixed-methods study which examined nurses' perceptions of FCC at a children's hospital in Sri Lanka, with a view to implementing FCC in the Sri Lankan health system. They found that most participants supported the concept of FCC and practiced some aspects of it in their daily work. The majority of nurses had not received any formal education on FCC, so their knowledge on the topic was limited. This research was conducted in a children's hospital in Sri Lanka, 157 nurses completed a self-report survey and 18 nurses participated in focus group interviews. The researchers concluded that there was a clear knowledge deficit which needs to be addressed if FCC is to be effectively implemented in the Sri Lankan healthcare setting. The results of this study may

not be generalisable as it was conducted at a single institution in Sri Lanka. Furthermore only nurses' views were explored, excluding the views of other healthcare professionals working with children and parents of hospitalised children. Additionally, Phiri *et al* (2022) reported that nurses with a postgraduate qualification were more likely to implement FCC in their daily practice, than those with an undergraduate certificate in nursing only. They investigated the extent to which nurses implement FCC using a cross sectional study design, collecting data from 444 nurses in the paediatric departments of two hospitals in Malawi using a validated tool - the FCCQ-R, and had a 100% response rate. The data were collected through self-reported questionnaires which may have led to biased responses.

Communication was identified as a barrier to effective implementation of FCC by a number of authors (Avis and Reardon, 2008; Coyne, 2013; Moore *et al*, 2015; Feeg *et al*, 2016; Alabdulaziz *et al*, 2017; Evans, 2017). A small qualitative study by Avis and Reardon (2008) in the UK explored parents' views on how their child with additional needs had been cared for in hospital, and identified that nurses need to communicate better with parents about their child's care and progress. Likewise, in a study by Coyne (2013, p. 803) both nurses and parents cited "over-reliance on parents and lack of communication" as barriers to effective implementation of FCC in the Irish context. Coyne (2013) asserts that nurses do not negotiate roles and responsibilities in a structured way with parents, which results in parents feeling confused about what care activities they should participate in. Similarly, Alabdulaziz *et al* (2017) found that nurses struggle to implement FCC, citing language differences, communication issues and cultural issues as barriers to its implementation in everyday practice in Saudi Arabia. This study used a mixed methods approach to explore FCC from the perspectives of children's nurses in six hospitals in Jeddah. Two hundred and thirty four surveys were distributed with a response rate of 93% (n=219). Qualitative data included non-participant observation of 14 nurses and individual interviews with 10 nurses. These researchers found that not all elements of FCC were implemented and that the nurses had "a limited understanding of what FCC means" (Alabdulaziz *et al*, 2017; p. 75). The nurses had received no formal education about the concept of FCC, instead they worked with the elements as a set of tasks which were implemented inconsistently. The Western model of FCC may not be appropriate in the Saudi Arabia setting, where both nurses and families are from non-Western cultures (Alabdulaziz *et al*, 2017). However, the authors advise that the findings may not be transferable to other settings due to the convenience sampling technique used and the very limited number of Saudi Arabian nurses who were available to participate in the study. Mothers, whose first language was not English, reported difficulty understanding communication from healthcare professionals in a study carried out in the USA using qualitative methods and content analysis to examine the hospital experience of 15 mothers of children who had a traumatic brain injury (Moore *et al*, 2015). There were significant limitations to this study including only the mothers'

perspective being included and a dependence on the participants' memory of the hospital admission, as the data were gathered months to years following the hospitalisation, which may have had potential for memory bias. Nevertheless, Evans (2017) reported similar findings when she examined parents' perceived satisfaction with their experience of nursing care in a PICU in California, USA, using a pre-intervention and post-intervention quasi-experimental design. Evans (2017) found that there was statistical difference between parents' perception of FCC and their perceived satisfaction with nursing care in PICU. She concluded that there was a need for improved communication between parents and nurses, suggesting that healthcare professionals need to increase parental inclusion in the care of their sick child in hospital. This finding was supported by Gangodage Done *et al* (2020) when they recognised that while nurses in Sri Lanka endorsed the concept of FCC and practiced some elements of it, they had poor communication skills and consequently were challenged when discussing care with families.

The cultural impact of FCC in practice was recognised by Boztepe and Kerimoğlu Yıldız (2017) in their study which explored nurses' views of FCC in Turkey. They found that the cultural characteristics of each family influenced how FCC is perceived, and that what is appropriate practice in Europe may not be appropriate in Turkey. The practice of FCC is culturally dependent not only on the country where care is being delivered, but also on the values of the child and family receiving care. Feeg *et al* (2016), in a multi-site comparative non-experimental study, identified staff attitudes and knowledge of FCC as barriers to its consistent implementation. These researchers surveyed 476 healthcare professionals including nurses, doctors and allied health professionals, in three countries (Australia, Turkey and the USA) using survey questionnaires, and reported that healthcare professionals prefer to work with children than with parents in all three countries, and are more concerned about the needs of the child than those of the parent. These researchers question how FCC can truly occur in an environment that does not view the hospitalised child and his/her parent as a single unit receiving care. This finding is consistent with that of Abdel Razeq *et al* (2020) in a cross-sectional descriptive study in Jordan, which examined the attitudes of 246 children's nurses working in the acute hospital setting toward family-centredness. Nurses had more positive attitudes towards working with children than with their parents, suggesting that nurses prefer working with children. These researchers concluded that applying FCC in Jordan may prove challenging because nurses may not embrace the concept of working with the child and their parents as a unit.

Support at management level within the organisation was also recognised as necessary to the effective implementation of FCC (Coyne *et al*, 2011; Coyne *et al*, 2013; Boztepe and Kerimoğlu Yıldız, 2017; Coats *et al*, 2018; Dall'Oglio *et al*, 2018; Segantini Felipin *et al*, 2018; Prasopkittikun *et al*, 2019; Gangodage Done *et al*, 2020). Coyne *et al* (2013)

suggested that nurses need support from management in order to implement FCC into their everyday practice. Similarly Boztepe and Kerimoğlu Yıldız (2017) in a qualitative study based in Turkey reported that nurses need to have sufficient resources and support from managers in order to implement a family-centred model of care effectively. Dall'Oglio *et al* (2018) also recognised that competing organisational priorities was a barrier to effective implementation of FCC in everyday practice. Furthermore, Segantini Felipin *et al* (2018) explored nurses' views of FCC in the NICU and PICU setting in Brazil and reported that all treatment decisions are made by the healthcare professionals, with no family involvement and that a policy of restricted visiting prevents parents' constant presence with their child in hospital. Coats *et al* (2018) explored nurses' views on the benefits and challenges of FCC in PICU, and found that the introduction of policies supporting family presence at the bedside and the transformation from open space to individual rooms, were enablers to implementing FCC. These researchers took a qualitative descriptive approach to exploring nurses' perceptions of the benefits and challenges of providing FCC in three different PICUs in an urban children's hospital in USA. Because of the small sample size (n=10) further research with more participants will need to be conducted in order to confirm the findings.

A mixed methods study by Prasopkittikun *et al* (2019) sought to identify the differences between children's nurses' perceptions of FCC and their current practices, and why differences still exist. This two-phase study was conducted in a university hospital in Thailand. In phase one, 254 children's nurses were surveyed using the FCCQ-R, of which 142 (56%) responded. In phase two 16 nurses from phase one were purposively selected to participate in semi-structured interviews based on the findings from phase one. Data from phase one were analysed using the SPSS, while data from phase two were analysed using thematic analysis. Prasopkittikun *et al* (2019) contend that while Thai nurses believe in the ideal of FCC, they do not implement it in their everyday practice. Thai nurses believe they are more knowledgeable in caring for hospitalised children than parents, and hence they assume a more active role in planning and delivering care. FCC was perceived as a Western ideal, and a shortage of nurses in this setting was recognised as a barrier to its implementation in practice. The authors concluded that some elements of FCC may not fit with the Thai model of healthcare, claiming that it is a Western model of care (Prasopkittikun *et al*, 2019). The FCCQ-R questionnaire was modified for use in this study without gaining validity or reliability of the tool, which is a limitation to the study. Furthermore it was conducted in Thailand, so the findings may not be transferable to other settings. Nonetheless, a shortage of nursing staff was also identified as a barrier to effective implementation of FCC by Gangodage Done *et al* (2020) who reported that the high nurse to patient ratio within the hospital was identified as a deterrent to the successful implementation of FCC, which the authors say needs to be addressed by hospital management in order to effectively implement FCC in the Sri Lankan context (Gangodage

Done *et al*, 2020). There were frequent references to nursing staff shortages in the literature in the context of it being a barrier to effective implementation of FCC in practice (Coyne and Cowley, 2007; Neal *et al*, 2007; Coyne, 2013; Lee and Lau, 2013; Feeg *et al*, 2016; de Macedo *et al*, 2017; Phiri *et al*, 2019; Prasopkittikun *et al*, 2019; Saria *et al*, 2019; Gangodage Done *et al*, 2020; Ohene *et al*, 2020; Phiri *et al*, 2020).

3.6 Discussion

This literature review provides a critical synthesis of research studies (n=62) that explored the views and experiences of FCC from the perspectives of the hospitalised children and parents receiving care and the nurses delivering care. An updated literature search conducted in October 2022 identified 17 additional studies which met the inclusion criteria and were published in the four-year period since the original search. Following analysis of these additional studies on FCC of hospitalised children, no new information came to light, the core issues remained unchanged and the original headings used to present the findings remained the same. This is a finding in its own right. After multiple studies on the topic, it appears that the same issues are emerging. Perhaps it is time that researchers examine FCC for hospitalised children and their families from a different perspective, in order to support or refute its continued practice.

This review revealed six key issues in terms of how FCC is understood by hospitalised children, their parents and the nurses caring for them. These issues were:

1. The needs of the family when their child is in hospital (Neal *et al*, 2007; Shields *et al*, 2008; Bellin *et al*, 2011; Lee and Lau, 2013; Baird *et al*, 2015; Roscigno, 2016; Seliner *et al*, 2016; Foster and Whitehead, 2017; Foster *et al*, 2018; Khaksar *et al*, 2022; Saria *et al*, 2019; Terp *et al*, 2021).
2. The value parents place on the development of a trusting partnership with members of the healthcare team (Avis and Reardon, 2008; Coyne *et al*, 2013; Phiri *et al*, 2019; Ohene *et al*, 2020).
3. Parents' willingness to participate in care (Coyne *et al*, 2013; Higham and Davies, 2013; Romaniuk *et al*, 2014; Schalkers *et al*, 2016; Cimke and Mucuk, 2017; Vasey *et al*, 2019; North *et al*, 2020; Ohene *et al*, 2020; Phiri *et al*, 2020).
4. The importance of parental presence to provide care in the context of helping the busy nursing workload (Hughes, 2007; Coyne and Cowley, 2007; Avis and Reardon, 2008; Coyne, 2013; Lee and Lau, 2013; Livesley and Long, 2013; Curtis and Northcott, 2017; Phiri *et al*, 2019; Prasopkittikun *et al*, 2019; Saria *et al*, 2019; Ohene *et al*, 2020).
5. The importance of parental presence to provide comfort, emotional support and reassurance for their child (Coyne and Cowley, 2007; Hughes, 2007; Ames *et*

al, 2011; Coyne, 2013; Higham and Davis, 2013; Romaniuk *et al*, 2014; de Macedo *et al*, 2017; Foster and Whitehead, 2017; North *et al*, 2020; Ohene *et al*, 2020; Fisk *et al*, 2022).

6. The many challenges and barriers to effective implementation of FCC in practice (Avis and Reardon, 2008; MacKay and Gregory, 2011; Coyne *et al*, 2013; Baird *et al*, 2015; Moore *et al*, 2015; Vasli *et al*, 2015; Alabdulaziz *et al*, 2017; Boztepe and Kerimoğlu Yıldız, 2017; Evans, 2017; Dall'Oglio *et al*, 2018; Segantini Felipin *et al*, 2018; Farokhzadian *et al*, 2020; Gangodage Done *et al*, 2020).

The fundamental principles of FCC identified in a concept analysis included: parental participation in care, the development of respectful and trusting partnerships, information sharing and all family members as care recipients (O'Connor *et al*, 2019). In practice, FCC is dependent on the parent being present at the bedside, and their willingness to participate in care. It is evident from this review that parents wish to participate actively in the care of their sick child in hospital, the degree to which they wish to do so varies, and needs to be negotiated between the nurse and each individual parent and child on an ongoing basis (Avis and Reardon, 2008; Coyne *et al*, 2013; Curtis and Northcott, 2017; Feeg *et al*, 2016; Saria *et al*, 2019; Vasey *et al*, 2019; North *et al*, 2020; Ohene *et al*, 2020; Phiri *et al*, 2020). Parents are sometimes expected to participate in their child's care without any discussion with the nursing staff, which can add to their stress. There is a growing body of evidence that families, specifically parents, play a vital role in the quality of care, satisfaction with care and patient safety for hospitalised children (Kuhlthau *et al*, 2011; Aragona *et al*, 2016; Bell *et al*, 2017; Mastro, 2017; Ahmann, 2018).

Despite this, many children's hospitals continue to see parents, whom the child relies on for physical, psychological, emotional and social support, as visitors. Some hospitals continue to restrict parental visiting, particularly in the PICU setting, but also on general ward areas during doctors and/or nurses rounds (Vasli *et al*, 2015; Boztepe and Kerimoğlu Yıldız, 2017; Hill *et al*, 2018b; Segantini Felipin *et al*, 2018). In one study there was a failure to accommodate parents who wished to stay by the bedside overnight in the PICU setting (Vasli *et al*, 2015). In viewing parents as visitors, nurses, and healthcare professionals in general, fail to see them as partners and members of the team caring for the sick child, which is a basic premise of FCC. Changing these practices is fundamental to the consistent and effective delivery of FCC. It is also recognised that in order for FCC to be implemented consistently and effectively, nursing leadership and the hospital executive team must have a clear understanding of the concept and provide explicit commitment and support to front-line nursing staff who are delivering care to the child and family everyday (Coyne *et al*, 2011; Coyne *et al*, 2013; Boztepe and Kerimoğlu Yıldız, 2017; Coats *et al*, 2018; Dall'Oglio *et al*, 2018; Segantini Felipin *et al*, 2018; Prasopkittikun *et al*, 2019; Gangodage Done *et al*,

2020). While it is widely accepted that hospitalisation is a stressful experience for children and parents due to fear and uncertainty about treatment and prognosis, this review found that parents may be more resilient than healthcare professionals believe (Shields *et al*, 2008; Roscigno, 2016). Parents appear to be more concerned with the needs of their child than with those of themselves.

The needs of the family, specifically parents, of hospitalised children, were also highlighted. It was reported by nurses that parents needed to be cared for as well as hospitalised children (Hughes, 2007), and some studies reported that parents experienced less stress when FCC was practiced well (Frost *et al*, 2010; Moore *et al*, 2015; Mortensen *et al*, 2015; Khaksar *et al*, 2022). Parental presence in the context of them providing emotional support for their child was also a key issue (Coyne and Cowley, 2007; Coyne, 2013; Boztepe and Kerimoğlu Yıldız, 2017; Curtis and Northcott, 2017; de Macedo *et al*, 2017; North *et al*, 2020; Ohene *et al*, 2020; Fisk *et al*, 2022).

In many studies parents felt obliged to stay with their child in hospital and participate in care, because the nurses appeared to be too busy to be available to the child when needed. It was also acknowledged that parents' participation in care can be helpful for nurses. This was especially evident in resource limited and developing countries, such as Malawi (Phiri *et al*, 2019; Phiri *et al*, 2020), Ghana (Ohene *et al*, 2020), Tanzania (Saria *et al*, 2019) and Thailand (Prasopkittikun *et al*, 2019), but also referred to in studies from other countries such as Brazil (de Macedo *et al*, 2017), China (Lee and Lau, 2013), Ireland (Coyne *et al*, 2011; Coyne *et al*, 2013), Sri Lanka (Gangodage Done *et al*, 2020), Turkey (Feeg *et al*, 2016; Boztepe and Kerimoğlu Yıldız, 2017), the UK (Coyne and Cowley, 2007) and the USA (Neal *et al*, 2007; Coats *et al*, 2018). Many researchers cited a shortage of nursing staff as a barrier to the effective implementation of FCC in practice (Coyne and Cowley, 2007; Hughes, 2007; Avis and Reardon, 2008; Coyne, 2013; Romaniuk *et al*, 2014; Feeg *et al*, 2016; Phiri *et al*, 2019; Prasopkittikun *et al*, 2019; Saria *et al*, 2019; Ohene *et al*, 2020). There is evidence that a perceived nursing staff shortage and the resultant busy nurses' workload, pose challenges to nurses attempting to apply FCC to their daily practice and contribute to its inconsistent implementation.

3.6.1 The need for further research

Like many social concepts, FCC is perceived in different ways depending on the cultural setting within which it is practiced. Furthermore, social concepts contribute to knowledge and practice in a more meaningful and useful way when they are studied within an identified cultural setting. Because major cultural variations exist worldwide, Bagnasco *et al* (2017) advise that an evidence-based framework, which is culturally specific, is needed to support the consistent and effective implementation of FCC in practice. With the establishment of a new children's hospital in Dublin which will serve the children and families of Ireland, and

the reconfiguration of children's healthcare services, the development of such a framework within the Irish context is timely and must be considered a priority. If change is to be effectively implemented then it must be supported by empirical research, and this research must be inclusive of those who will be affected by any new practices, including children and their parents.

Most studies included in this review investigated the parents' and/or health professionals' experiences of FCC, and did not include the child's views and experiences. One study (Livesley and Long, 2013) examined the child's experiences of hospitalisation, while a further three studies (Coyne and Cowley, 2007; Coyne, 2013; Curtis and Northcott, 2017) sought the views of children, their parents and nurses on participation in care and their experiences of FCC in the acute hospital setting. Too often the views of parents are considered to represent those of their children. Further research must include the voice of hospitalised children as research participants. Given that the literature examined in this review suggests that hospitalised children and young people have not been widely consulted as participants in previous research, an important aspect of my proposed study will be to explore children's and young people's experiences of being in hospital from their perspective. It will also examine the broader social and cultural contexts of healthcare delivery, in order to be more reflective of the healthcare needs of the children and families accessing health services in Ireland in light of current migration trends internationally.

The vision for children's healthcare, as outlined in the National Model of Care for Paediatric Healthcare Services in Ireland (Nicholson and Murphy, 2015), includes care closer to home, increased day-case activity, early discharge and consequently increased patient throughput. This will result in increased patient acuity in the in-patient setting. Earlier discharge will reduce the time children and parents will spend in hospital. The pressure of containing costs and increasing patient throughput have been recognised as challenges to the delivery of high-quality patient and family focused healthcare (van Dam *et al*, 2013; Jakimowicz *et al*, 2017). Such challenges are particularly relevant to children's nurses today, as they strive to implement FCC effectively, within the challenges of increased day-case activity, early discharge and increased patient throughput.

3.7 Chapter summary

This chapter began with identifying the need for a literature review. The systematic approach to the literature search was described in detail. The empirical literature on FCC for hospitalised children and their parents was critically examined, which indicated the need for further research into their experiences and expectations while in hospital. Empirical evidence must be generated, exploring the experiences and expectations of FCC for hospitalised children and their parents, in order to promote consistent and effective implementation of a model of care that is truly child- and family-centred. The child is likely

to provide a different perspective to that of their parent. This research must also examine the role of children in their own care in hospital, and that of their parents. Research investigating the perspectives of both hospitalised children and their parents will give a wider view of what FCC means to those receiving care and offer some insights into their expectations. This knowledge will inform future care for hospitalised children and their families.

The next chapter will be presented in two parts. In Part One the researcher's philosophical underpinnings and worldview will be presented. The chosen methodology will be discussed in detail, and an outline of the evolution of grounded theory will be given. The applicability of a constructivist grounded theory approach (Charmaz, 2006; 2014) to explore children's, adolescents' and parents' experiences and expectations of their roles in hospital will be explained. In Part Two, a description of the specific tools used to undertake the research will be detailed. A discussion on how the research site was accessed, how the ethics approval and gatekeeping processes were navigated before conducting this research, will be presented. The method of sample selection, data collection and analysis will be outlined in detail. Reflexivity and the role of the researcher is also addressed.

Chapter 4

Research Methodology and Methods

“Every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously.”

(Article 12: United Nations Convention on the Rights of the Child, 1989)

4.1 Chapter Four - Part One – Research methodology

4.1.1 Introduction

All research is based on the researcher's underlying philosophical view about what constitutes knowledge and knowing. This underlying worldview will inform the research design, as well as the methodology and methods appropriate for the development of knowledge in a given study. In order to evaluate a research study, it is therefore important to know the worldview of the researcher. In Part One of this chapter I will discuss my own philosophical worldview and assumptions which underpin this study. The most common philosophical assumptions will be presented, with a rationale for why they were not appropriate for this study. Why the constructivist paradigm was identified as the framework for the study will be explained, including what influenced me to use this approach. The rationale for the use of constructivist grounded theory as the chosen methodology will be outlined in detail. Associated research methods and my reflections on the research process will be presented in Part Two of this chapter.

This research is situated within existing research traditions in nursing. The aim of this study was to explore children's/adolescents' and their parents' experiences and expectations of their roles while in hospital. The objectives were to:

1. Identify children's/adolescents' experiences and expectations of their parents' involvement in their care in hospital.
2. Explore children's/adolescents' experiences of engagement and role preferences in their own care in hospital.
3. Explore parents' experiences and expectations of their role in their child's care in hospital.
4. Explore parents' perspectives of their child's role in their own care in hospital.
5. Develop a theory to explain the involvement of the child/adolescent and parent in care in hospital.

The findings will enhance our understanding of the concept of child/adolescent and parental involvement in care while in hospital, and inform children's nursing practice.

4.1.2 Philosophical perspectives

Bowling (2014) defines research as a systematic and rigorous process of inquiry which aims to develop explanatory concepts and theories, and contribute to an evidence-based body of knowledge that can enhance our understanding of the phenomena being studied. A researcher's underpinning philosophy influences how he/she conducts research, in other words the position the researcher takes in the study is directly associated with his/her philosophical worldview and informs the research design, methodology and methods (Creswell and Creswell, 2018). Creswell and Creswell (2018; p.5) advise researchers to

“make explicit the larger philosophical ideas they espouse” before proceeding with the research. According to Denzin and Lincoln (2018), depending on the philosophical beliefs of the researcher and the adopted methodology, researchers take either a position of distance or acknowledged inclusion in the data collection process, analysis of the data and the final reporting of the findings. Philosophical perspectives influence how a phenomena should be studied. Examining and acknowledging one's worldview prior to conducting research, promotes identification of the types of data that need to be gathered, how they should be collected and subsequently interpreted (Weaver and Olson, 2006). Philosophical perspectives include the concepts of ontology and epistemology. Ontological and epistemological aspects concern what is commonly referred to as a person's worldview and have significant influence on whether one views reality in an objective or subjective way.

4.1.2.1 Ontology

Ontology refers to how one views reality and how we understand what exists and is experienced (Rodriguez and Smith, 2018). Ontology answers the questions “What is the nature of reality?” and “Where do we look for it?” (Blaikie, 2007). The two most dominant ontology positions are the realist ontology and the idealist ontology, with various ontological stand points along that continuum. Realist ontologists believe only objects or events that can be observed actually exist, and that descriptions of them are generalisable (Blaikie, 2007). Realist ontology assumes that the phenomenon being studied is independent of the researcher. The idealist ontology perspective on the other hand, believes reality is what people make or construct. Constructions of reality are different ways of perceiving and making sense of the world we find ourselves in. As humans we live within a culture of shared experiences. Our behaviours give meaning to our worlds, and these meanings and interpretations make up our social reality (Blaikie, 2007). Subjective ideas are accepted as real by those who believe them.

My perspective aligns closely with the idealist ontology. I believe reality is what we as inhabitants of that reality make of our social situation, and results from our interactions with others in our social world.

4.1.2.2 Epistemology

Epistemology refers to how knowledge is developed, what counts for valid knowledge and relates to how people come to have knowledge of the world around them (Creswell and Creswell, 2018). Epistemology answers the question “How can reality be known?” and informs the most appropriate methodology and methods to produce the evidence needed to explain the phenomenon being studied. Researchers who adhere to the objectivist epistemology believe that all researchers will discover the same meaning and truth about things (Blaikie, 2007). On the opposite end of the continuum, subjectivists acknowledge that

they impose their own meaning on the topic being studied. Meaning may be interpreted differently by different researchers. Along that continuum constructivists are situated and recognise that meaning is constructed rather than discovered, that the researcher and the research participants actively create meaning and knowledge together.

The constructivist epistemology holds resonance for me as a researcher. I believe new knowledge is context and time dependent, and I acknowledge the part the researcher plays in its discovery through interpretation of the participants' data.

4.1.2.3 Positivism

Researchers operating from a positivist paradigm believe in a single, objective, unchanging reality, aiming to discover what makes the world work (Nicholls, 2009a). Positivists take a realist and objective view of human and social phenomena, believing that a single absolute truth is out there to be found by conducting controlled experiments and applying deductive reasoning to the data. An essential aspect of sound positivist research is that of the researcher holding an objective position within the research process, where he/she remains distant from, and independent of, the subjects being studied (Bryman, 2016). In this way researchers attempt to ensure the findings are free from any possible researcher bias. These researchers adopt an "objectivist" perspective, a belief in an objective real world, objectively seeking to find the effect of an intervention, rather than an explanation or understanding of a social phenomenon. Positivist research methods consist of objective and systematic observation and experimentation in order to arrive at objective, empirical findings by controlling the contextual variables (Weaver and Olson, 2006). Early nurse researchers followed this paradigm to develop a scientific knowledge base in nursing, when nursing was still attempting to gain professional status in a world dominated by medicine and academia (Weaver and Olson, 2006). Validity, reliability and generalisability are considered important measures when assessing the quality of this type of research (Bryman, 2016).

My research sought to understand children's/adolescents' and parents' experiences and expectations of their roles while being an in-patient in a children's hospital in Ireland. I believe that the participants, as unique individuals, bring their own interpretations of their experiences to the research, and that there is more than one reality. Rather than being free from researcher bias, I acknowledge any preconceived assumptions and outline them in the final report. These assumptions are seen as contributing to the findings in terms of the contextual setting, rather than adding researcher bias to them. Furthermore, the findings are not generalisable, rather they are trustworthy and may be transferable to other similar settings, as determined by the reader. Consequently, positivism does not fit with my personal philosophy or with this research question.

4.1.2.4 Post-positivism

Researchers operating from the post-positivism paradigm fail to acknowledge the importance of the contribution made by the participants and researchers to the research process and the resultant findings (Nicholls, 2009a). Post-positivist researchers challenge the traditional idea that knowledge is absolute truth, and contend that our social world is actively constructed by humans; that we are constantly attempting to make sense of our social environment, which is a dynamic constantly evolving process (Parahoo, 2014). They also claim that reality may never be fully understood, because of the many hidden variables inherent in our world. For them, knowledge is an attempt to get as close to the truth as possible by approximating reality and developing a better understanding of the phenomena being studied (Lincoln *et al*, 2018). Those who operate within this paradigm consider objectivity as an important feature of their research, so that their research produces valid and reliable findings. They attempt to achieve it by keeping their interactions with their research subjects, rather than research participants, to a minimum (Lincoln *et al*, 2018). They also rely on multiple methods of data collection to capture as much of reality as possible, with the emphasis on the discovery and confirmation of new theory and knowledge (Denzin and Lincoln, 2018). Post-positivist researchers include large numbers of subjects in their sample, using statistics and deductive reasoning to interpret their findings, aiming to get as close as possible to reality and fact. Thus the findings from post-positivist research are said to be generalisable. While these researchers acknowledge context in terms of participant demographics and socio-political data, they do not acknowledge the importance of the contribution the participants and researchers bring to the research process, and to the construction of new knowledge. As a result the process and findings are stripped of resonance and meaning for the participants. For these reasons the post-positivist paradigm does not suit my personal research philosophy or this research problem.

4.1.2.5 The transformative paradigm

The transformative paradigm as a worldview focuses on the needs of individuals and groups who may be oppressed in some way. It aims to create a more fair society by improving social justice and removing barriers associated with social oppression (Lincoln *et al*, 2018). Researchers who operate from this paradigm are concerned with empowering marginalised groups of people to overcome the constraints placed on them by race, class or gender (Creswell and Creswell, 2018). They examine issues of equality and social justice, power and alienation, discrimination and oppression. Researchers who are critical theorists, participatory action researchers, feminists, members of racial and ethnic minorities, people with disabilities, members of lower socio-economic groups and members of the lesbian, gay, bisexual, transgender and questioning (LGBTQ) communities operate from this paradigm (Creswell and Creswell, 2018). These researchers work collaboratively with the

research participants, giving them a voice in order to influence social policy and minimise any further marginalisation. They search for new opportunities for the participants, believing that research must be intertwined with politics and the social justice reform agenda. Transformative researchers seek not only a better understanding of their area of research, but also to bring about social transformation as a result of their research (Nicholls, 2009a). Research carried out within this paradigm is considered to have been valid when outcomes include action and positive social change for the participants, leading to a more fair and just society (Lincoln *et al*, 2018).

While my research includes the voice of the participants, hospitalised children/adolescents and their parents who are experiencing the phenomenon under study, their involvement in care while in hospital, it is not related to any social or political agenda. Furthermore, while the research participants are vulnerable by virtue of being ill and in hospital undergoing medical and/or surgical treatment, they are not considered a marginalised group. Some of them may be marginalised if they are homeless, members of the travelling community or the LGBTQ community, but being in hospital does not marginalise them. For these reasons this paradigm cannot be applied to this study.

4.1.2.6 Pragmatism

Pragmatism as a research philosophy focuses on problem solving, contending that most research topics are best viewed in terms of their practical uses. Pragmatists assume that people are active in providing solutions to their own problems, and it is through these actions that we create knowledge (Charmaz, 2014). This practical approach to research allows the researcher to apply many different methods to collect subjective and objective information, including both quantitative and qualitative data. According to this paradigm, the best understanding of the research problem will be achieved by using multiple approaches to data collection and analysis (Creswell and Creswell, 2018). This broad approach allows the researcher to use a “what works” perspective to explore and understand complex phenomena from many different points of view. Pragmatists reject the existence of a single truth and a single research method, instead placing an emphasis on consequences, practical results and diversity of views and methods (Rodgers, 2018). Pragmatism is a practical approach to research that supports mixed or multiple methods for social science research.

From a concept analysis and literature review conducted during the early stages of this research study, it appeared that a clear understanding of the concept of family-centred care (FCC) is lacking internationally, leading to its inconsistent application in practice. The aim of this study was to explore children’s/adolescents’ and parents’ experiences and expectations of their roles while in hospital. While the participants will be co-creators of the new knowledge generated from this research, they will not be providing the “solution” to the

lack of definition and consistent application in practice, as is a feature of pragmatism. Hence, pragmatism is not a suitable worldview to underpin this study.

4.1.2.7 Constructivism

Constructivist researchers believe that multiple realities exist and these realities are constructed through the meanings and understandings given to them by those who find themselves in a given social setting. In other words, reality is dependent on individuals, their experiences and their social context (Mills *et al*, 2006; Johnson and Webber, 2014). Constructivists value observed and perceived phenomena, acknowledging that different people may have different interpretations of the same phenomenon (Johnson and Webber, 2014; Parahoo, 2014). Thus, to be truly understood, phenomena must be studied in context. Researchers assuming a constructivist paradigm are concerned with understanding the world as it is viewed from the subjective experiences of the individuals who participate in the study. They believe that one's personal reality is constructed by one's own understanding of reality, or in the words of Guba and Lincoln (1985; p. 73) that "We put together our own personal reality". Guba and Lincoln (1989) claim that the work of constructivists leads to the creation of new explanations or understandings of phenomena through discussion with the participants. The resultant new knowledge is co-shaped, or co-constructed, by the values and attitudes of the participants and the researcher. The researchers' interpretation of the participants' stories is overtly acknowledged in constructivist research (Charmaz, 2014). Guba and Lincoln (1989) argue that to remove the context by controlling the variables would be to strip the experience of meaning for the participants, claiming that it is impossible to make sense of these human interactions without getting close to the participants. This notion is also supported by Lincoln *et al* (2018), who assert that constructivist researchers influence the outcome of the study by contributing to theory development during the process of data gathering and analysis. The end result of constructivist research aims to bring about a positive change in practice in the long-term, and in a more reflective way than transformative research (Lincoln *et al*, 2018).

Constructivist research usually focusses on a single concept or phenomenon and is conducted in the field by in-depth and up-close examination of the phenomenon of interest. This paradigm is underpinned by observation and interpretation; to observe is to collect data about the phenomenon, while to interpret is to make meaning of that information, by drawing inferences or by creating and refining patterns from the data (Kwadwo Antwi and Hamza, 2015), through inductive reasoning. Inductive reasoning begins with a broad research question, with the researcher seeking to discover an understanding through listening and observing, ultimately generating new knowledge to provide a better understanding of the original research question (Nicholls, 2009a). Constructivist researchers use meaning oriented methodologies, such as interviewing or participant observation, and position

themselves within the context of the phenomenon being studied, acknowledging the relationship between them and the participants. They believe that new knowledge is found in the interactions between persons and within social settings, rather than the interpretation of statistics (Johnson and Webber, 2014). Constructivist researchers immerse themselves in the research process, their personal values, beliefs and experiences will always be reflected in the new knowledge generated, which is reflective of the participants' reality (Lincoln *et al*, 2018).

Within this paradigm there is an assumption that the researcher cannot separate him/herself from what he/she already knows. According to Lincoln *et al* (2018) constructivist researchers must understand the social and cultural contexts in which the data are collected, in order to accurately reflect the participants' meanings and understandings. The accuracy of the new knowledge is reached by seeking agreement from the participants that the interview transcripts accurately reflect the discussion between the researcher and the participant during the research interview. It is further enhanced by inviting the participants to comment on whether the findings reflect their experiences (Noble and Smith, 2015).

Constructivist researchers place priority on the phenomenon being studied and consider that both data and analysis are created as a result of shared experiences with participants and data (Charmaz, 2014). All data are valid, what may hold significant meaning for one person, may hold little or no meaning for another in the same setting. Lincoln *et al* (2018) contend that once a participant can find the interpretation of the data to be an accurate reflection of their reality, then there is no such thing as invalidity of data or method. Constructivists believe that research is not only context-dependent, but is also time-dependent, and knowledge is continually evolving. Consequently, findings from research conducted within this paradigm are not time or universally valid, rather they are valid for the time and social context in which the data were collected, and by the individuals or participants who experienced them at that time. Hence, constructivist research is not considered to be generalisable, instead it is described as transferable to a similar population, experiencing a similar phenomenon, within a similar timeframe. Transferability is determined by the readers, who consider if the context and setting are sufficiently similar to their practice to be transferable to their setting. Constructivists seek to develop research that is credible, transferable, dependable and confirmable (Denzin and Lincoln, 2018).

The constructivist paradigm fits with my personal philosophy because I believe there are multiple realities out there to be discovered. I am interested in attempting to understand the experiences of others as seen from their perspective. In order to achieve such an understanding I believe phenomena must be studied in context, by getting close to the participants and listening attentively to their story. The constructivist paradigm acknowledges my interpretation of their data. I believe knowledge is constantly evolving

and context-dependent, what is reported as important and valid to one group of people in a given setting, may not be relevant to a similar population in a different setting. This study was situated within the constructivist paradigm, where both the participants' view of reality and my prior knowledge and experience were valued, and their influence on the research process was acknowledged (Charmaz, 2014). Rather than placing myself outside the research, I will engage in the process with the participants to ensure the findings are reflective of their realities. The aims and objectives of this study, together with my worldview, lend themselves to a qualitative approach, where the researcher seeks to understand the world in which the research participants live and work, through their personal experiences (Nicholls, 2009a; Denzin and Lincoln, 2018).

4.1.3 My worldview

My personal *modus operandi* is from a constructivist philosophy, which has been described by Guba and Lincoln (1989; p. 8) as a move away from

“Descriptions of the “way things really are” or “really work” and a move towards meaningful constructions that individual actors or groups of actors form to “make sense” of the situations in which they find themselves”.

Congruent with the writings of Mills *et al* (2006) I believe we are all influenced by our personal life experiences which shape our view of reality and our world. Constructivists explore the meaning of truth not only from the perspectives of the research participants, but also from that of the researcher, leading to some subjectivity in the results, which requires researchers to examine their own worldview (Polifroni, 2018).

I believe that there is no single truth out there to be discovered. These assumptions of our world can exist in our subconscious and be taken for granted. My research aims to identify a representation of the truth for a particular group of people (hospitalised children/ adolescents and their parents), who have experienced what it is like to be an in-patient in a children's hospital in Dublin, Ireland. I am influenced by the writings of Denzin and Lincoln (2018; p.106) who believe that truth is “partial and incomplete.” These scholars believe the research world has arrived at an era of emancipation, where we no longer see the world in black and white, but through a kaleidoscope of many colours. I see value in the many research paradigms that are described in the literature, respecting each one's valuable contribution to knowledge. However, I also openly accept the influence my philosophical viewpoint has on my own research. If my research findings are to be trustworthy and credible, I must be honest and transparent about my philosophical worldview, and remain true to it in the methodology and methods I choose to examine the phenomenon.

As an experienced children's oncology nurse, who has always been passionate about involving, supporting and working with children and parents as valued members of the team caring for the hospitalised child, I believe I have a clear understanding about the context of the phenomenon being studied. Additionally, I worked for more than a decade in the hospital where the data were gathered, in fact one of the clinical areas where I worked before moving to the oncology unit was a site for data gathering for this study. This experience provides further insight into the culture and context of the study setting. I am also a mother who has been in this hospital with my daughter on two occasions for minor procedures, once when she was five years old and again when she was 14 years old. During these short hospital stays we were never asked if we wished to participate in any care activities. It seemed there was an assumption that since I was staying with my daughter, I was willing to carry out her basic daily care. At no point was there a conversation to determine our roles, my role or my daughter's role, in her care in hospital. Collectively, these experiences have left me wondering if there is a better way to care for children and their parents in hospital, and inspired me to examine this phenomenon in greater detail.

This study explored the experiences and expectations of being in hospital for children/adolescents and their parents. It explored how they are supported and empowered to be engaged in their own care and to what extent they wish to participate in their own care. The experience of being in hospital with a sick child from the parents' perspective is also examined, including their expectations. Constructivism is considered the most appropriate worldview to underpin this research because it acknowledges that there are multiple realities out there to be explored, and that all realities are contextually and culturally dependent. My research findings are constructed jointly by the research participants and I, as researcher. Constructivism recognises the part played by both the researcher and the participants in co-constructing new knowledge, which is also time and context dependent. New knowledge generated within this paradigm is constantly evolving, leading to increasing uncertainty (McGhee *et al*, 2007) and further questioning.

4.1.4 Qualitative research

In the healthcare context, qualitative research is exploratory in nature, aiming to explore a phenomenon from the participants' perspective (Parahoo, 2014). It relies on data collection methods which allow the researcher to get up close to view the participants' world from their perspective, and includes data gathered through interviews, observation, group discussions and analysis of video-recordings, letters, diaries, case notes and other documents (Parahoo, 2014). According to Wong *et al* (2004; p. 311) qualitative research:

“... seeks to understand and interpret personal experiences, behaviours, interactions and social contexts to explain the phenomena of interest, such as the attitudes, beliefs and

perspectives of patients and clinicians; the interpersonal nature of caregiver and patient relationships; the illness experience; or the impact of human suffering”.

Qualitative research is particularly suitable when seeking to explore and explain why actions and interventions are, or are not, meaningful, appropriate or effective from the perspective of the patient or client (Lockwood *et al*, 2017). The qualitative researcher listens to the participants and seeks a deeper understanding of their experiences based on what he/she has heard, and how he/she interprets what has been heard. The focus is on learning about the meaning the participants place on the phenomenon they are experiencing. It offers ways of understanding the complexity of an individual's unique experience of health and illness, addressing issues particular to nursing and allied healthcare, which are not well addressed by a quantitative approach (Nicholls, 2009b).

Qualitative researchers systematically gather data themselves in the field where the research participants experience the phenomenon that is being examined (Denzin and Lincoln, 2018), by talking directly to the participants and/or observing how they behave in their natural settings (Creswell and Creswell, 2018). They analyse the data themselves using inductive reasoning and building patterns, codes, categories and themes which are common across the data sources, organising the data into more refined units of information (Creswell and Creswell, 2018). This process is achieved through working back and forth through the data, often during the data collection phase, until a comprehensive set of themes is reached and new theory is generated. The raw data may be reviewed again to determine if more evidence is needed to support each identified theme or category, and whether additional data needs to be collected. The qualitative research process is emergent and flexible. Creswell and Creswell (2018) advise that during a qualitative research study some of the initial plans may change. For example, the interview questions may change, or the forms of data collection may be modified after data collection first begins. These changes are as a result of the researcher learning more about the phenomenon from the participants, and recognising that modifications need to be made to the data gathering process in order to collect relevant information to address the research problem.

A qualitative approach was considered the most suitable approach for this study because it allowed me, as researcher, to speak with the children, adolescents and parents to examine what it was like for them to be in hospital, and to understand and interpret their experiences. I collected data by talking directly to the children and adolescents in the hospital where they were in-patients. I also interviewed their parents. The interviews were guided by the use of open-ended questions and a flexible and emergent interview guide, all of which are key features of qualitative research.

4.1.5 Research methodology

Qualitative research studies are informed by a range of methodologies or strategies, three of which were considered for this study: phenomenology, ethnography and grounded theory.

4.1.5.1 Phenomenology

First described by Husserl, now referred to as descriptive phenomenology, and further developed as interpretive phenomenology by Heidegger, this research methodology describes how the participants interpret their “lived experiences” about the phenomenon being studied (Rodriguez and Smith, 2018). Phenomenological research is concerned with understanding the ways in which people experience their world, their relationships with others and their environment. It aims to understand the lived experience as it is understood by those experiencing it (Cooney, 2010). The research question will typically ask “What is it like to live with ...?” Phenomenological research provides a rich and detailed description or interpretation of what it means to live in a particular world, experiencing a particular phenomenon (Creswell and Creswell, 2018; Rodriguez and Smith, 2018). Data analysis results in a description of patterns and relationships which explain what it is like to live in the studied world (Creswell and Creswell, 2018). This current study aims to move beyond a description of the experiences of the participants. Instead it aims to understand their experiences and expectations of their involvement in their own care while in hospital and develop an explanatory theory. Hence, phenomenology was not considered a suitable research methodology for this study.

4.1.5.2 Ethnography

Ethnography is an approach to research that seeks to understand how individuals interact within their own distinct cultural and social environment. Ethnographers identify a group of people who share a particular culture and collect data in the natural setting, through participant observation, field notes and interviews, usually over an extensive period of time (Creswell and Creswell, 2018). Ethnography allows the researcher to study how and why a distinct group of socially or culturally similar people behave the way they do, and examine how their behaviour is influenced by their cultural and social environment (Parahoo, 2014). Ethnographers study localised cultural experiences by getting close to, and being involved in, the participants’ environment, seeking to gain an insider’s understanding of their world, drawing conclusions about how societies function (Charmaz, 2014). Data analysis involves looking for patterns and themes in the data to explain why the participants behave the way they do. This current study aimed to capture the views and experiences of a socially and culturally diverse group of people who are experiencing the same phenomenon, being an in-patient in a children's hospital in Dublin or being with their child as an in-patient in hospital. Ethnography was not a suitable methodology because it aims to study groups of people in

their cultural environment. The participants in this study may not share a similar cultural or social background with each other.

4.1.5.3 Grounded theory

Grounded theory was considered the most suitable research methodology for this study because it supports the inductive, emergent and comparative approach (Glaser and Strauss, 1967) required to meet the study aim and objectives. This qualitative methodology is appropriate to explore the meanings that children/adolescents and their parents place on their experiences within the context of being in-patients in a children's hospital. It also supports how they interpret their experiences by telling their own stories, where the participants share their experiences and the researcher interprets the data. Within the constructivist paradigm and in keeping with grounded theory methodology, the participants and the researcher together co-construct the emerging theory from a position of acknowledged subjectivity as described by Charmaz (2014). Grounded theory can be used to examine new and emerging areas in need of research, as well as to gain fresh insights and perspectives on old familiar phenomena (Stern, 1980; Corbin and Strauss, 2015). FCC is not a new phenomenon in the world of children's nursing, however we know it is applied in practice in an *ad hoc* and inconsistent manner (Coyne *et al*, 2011; Coyne, 2013; Coyne *et al*, 2013; Feeg *et al*, 2016; Boztepe and Kerimoğlu Yıldız, 2017; Smith *et al*, 2017; Coats *et al*, 2018). The research presented here examined FCC from a new perspective: how children and adolescents wish to be included in their own care while they are in-patients in the acute hospital setting in Ireland. It also examined how their parents wish to be involved in their child's care in hospital. The aim was to develop a theory, grounded in the participants' own data, to explain what child and family involvement in care means to the participants.

4.1.5.3.1 Classic grounded theory

Grounded theory was first described by Glaser and Strauss (1967) as a research methodology which generated theory from qualitative data, and has become known as traditional or classic grounded theory. It was developed in response to tensions between quantitative and qualitative social researchers in the early 1960s in the United States of America (USA). During that time the dominant research philosophy was positivism and quantitative research was considered the gold standard in research practice, producing valid scientific knowledge which was generalisable across multiple settings. Classic grounded theory attempted to move qualitative research from a descriptive to an explanatory theoretical study, by providing an abstract understanding of the phenomenon being researched (Charmaz, 2014).

Qualitative research was generally considered the poor relation to quantitative research, because it was not objective and the findings were not considered generalisable

(Sandelowski, 1997). Glaser and Strauss (1967) developed systematic methods for qualitative research practice, which researchers could use to study many topics to develop theories from qualitative data, rather than testing hypotheses from an existing theory. Their systematic collection, coding and analysis of data resulted in the development of data collection and analysis techniques which attempted to bring some of the objective logic and rigour of quantitative data analysis to qualitative data, at a time when qualitative research was not very highly regarded (Glaser and Strauss, 1967). Simultaneous data collection and analysis, the use of the constant comparative method of data analysis, initially comparing data with data, to generate codes and categories from the data, moving back and forth through the data and preliminary codes, memo-writing to develop and refine the categories and theoretical sampling are key features of classic grounded theory (Glaser and Strauss, 1967). The goal of this methodology is to generate theory following the systematic collection, coding and analysis of qualitative data. An important feature of classic grounded theory is that the researcher enters the field of inquiry without any preconceived ideas in order to minimise the risk of personal bias, or researcher influence, in an attempt to maintain as much objectivity as possible. Classic grounded theorists believe in a single reality, which can be observed and discovered by a neutral researcher (Birks *et al*, 2019). Consequently conducting a literature review prior to data gathering is not encouraged, as Glaser and Strauss (1967) believed doing so would impose preconceived ideas on the researcher and contaminate the data.

4.1.5.3.2 Evolved grounded theory

Differences of opinion began to become evident between Glaser and Strauss, and a revised approach to the original classic grounded theory was described by Strauss and Corbin (1990), which has become known as evolved grounded theory. Corbin and Strauss (2015) assert that it is not possible for the researcher to be completely free from personal biases, arguing that it is unreasonable to expect any researcher to enter the field of inquiry without pre-existing professional and theoretical knowledge, and very often experience, on their chosen topic. They recognise the possibility of pre-existing views, and offer a variety of techniques such as questioning, reflexivity and making comparisons, to minimise researcher bias, especially during data analysis. Another key difference between classic and evolved grounded theory is the use of axial coding during data analysis, which involves refining categories into smaller multiple sub-categories, and re-assembling the initial codes to form a coherent whole (Strauss and Corbin, 1990). The purpose of axial coding is to enhance theory verification. Glaser (1992) was critical of the use of axial coding, arguing that it forced the data rather than allowing the theory to emerge from the data. He also claimed that axial coding was unnecessary as theoretical coding weaved the coded data back together to form the theory (Glaser, 1992).

In their seminal work *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* (Strauss and Corbin, 1990) and in its subsequent editions (Strauss and Corbin, 1998; Corbin and Strauss, 2008; Corbin and Strauss, 2015), the authors promote a flexible use of the strategies, suggesting that they are more like guidelines than rigid rules, advising researchers to use them in their own way to address the research question, while staying within the general guidelines. This approach allows for interplay between the researcher and the data, and gives a voice to the participants by acknowledging their views of reality. Corbin and Strauss (2008) promote the use of unstructured or semi-structured interview questions, claiming that this approach will allow the participants to speak freely about their experiences. Evolved grounded theory has been shaped by more recent methodological thinking, recognising the importance of being attentive to the contextual setting where the data are to be collected (Corbin and Strauss, 2015).

The flexibility inherent within the process and the acknowledgement of the researcher's influence on the emerging theory are just some changes that have developed over time. Evolved grounded theory recognises that not every study will result in a theory, some researchers will use a grounded theory approach to produce a new description of a phenomenon (Corbin and Strauss, 2015). These developments over time suggest that evolved grounded theory is more reflective of a contemporary constructivist philosophy, or as Mills *et al* (2006; p. 25) assert there is “a discernible thread of constructivism in their approach”. In contrast Glaser (1992) argues that grounded theory should not be changed, and that theory should be allowed to emerge from the raw data. He has also accused Strauss and Corbin of altering the original version so much that it can fail to produce a theory grounded in the data (Glaser, 1992).

4.1.5.3.3 Constructivist grounded theory

Later Professor Kathy Charmaz (2006) described constructivist grounded theory, which recognised the subjectivity brought to the process by the researcher. Charmaz (2006) suggested that openly acknowledging the researchers' preconceptions, which have developed as a result of his/her personal and professional knowledge and experiences to date, will add rigour to the study. In this way, meaning and theory are constructed as a collaboration between the researcher and the research participants (Charmaz, 2014). Constructivist grounded theory retains many of the features of the original classic grounded theory. The key differences are that there is greater attention to data collection, representation of the participants' contribution, and reflexivity about the researcher's role in the process (Charmaz *et al*, 2018). In constructivist grounded theory, reality is constructed through the meaning the participants make of the phenomenon and the researchers' interpretations and findings during data analysis (Charmaz, 2014). The emerging theory is

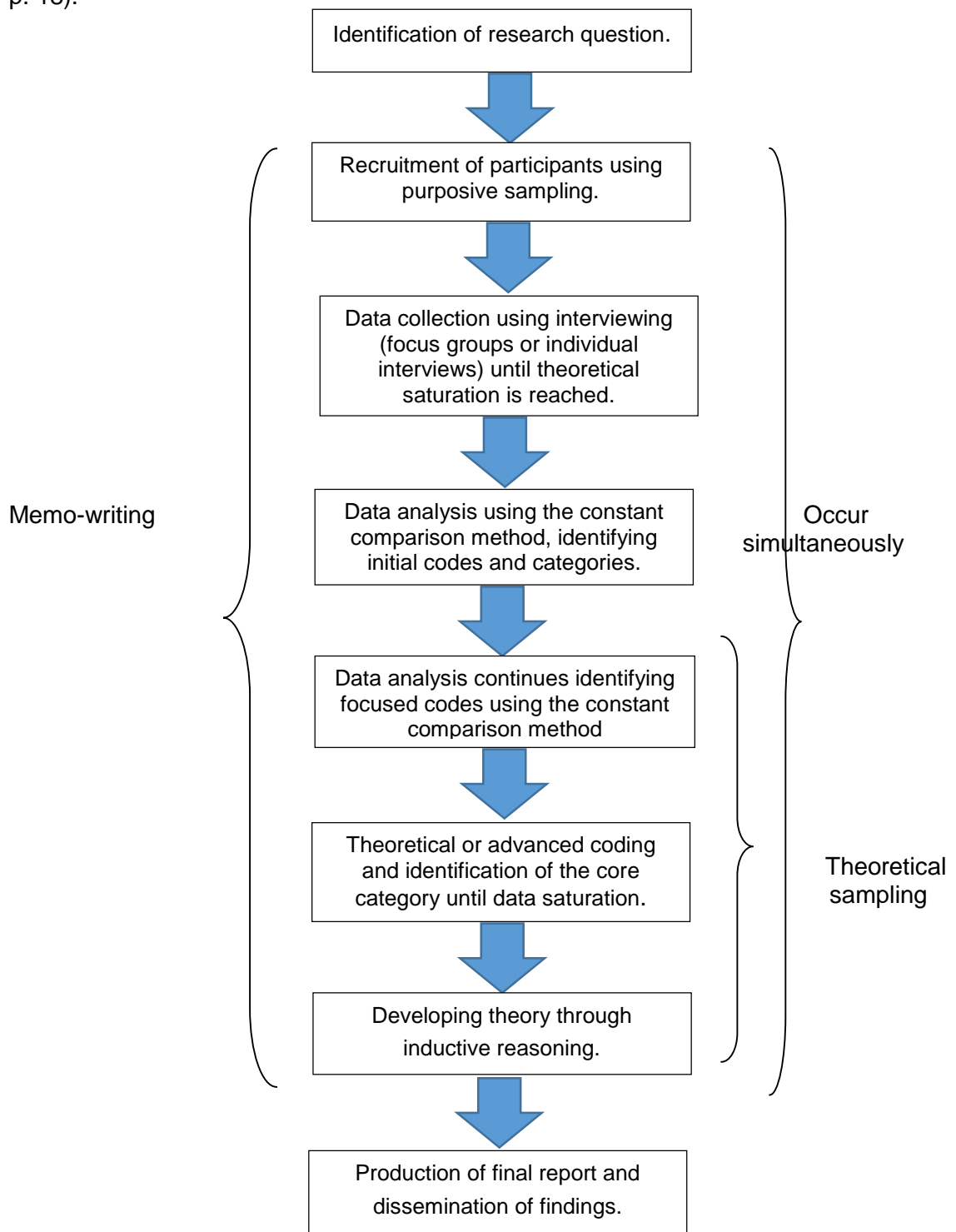
the result of interactions between the researcher and the participants. Data analysis includes initial coding and focused coding. Either or both theoretical coding, as described by Glaser and Strauss (1967), and axial coding (Strauss and Corbin, 1990) can be used in constructivist grounded theory.

Constructivist grounded theory is a systematic and flexible method for collecting and analysing qualitative data with the ultimate goal of developing theory to explain a particular social process and provide an improved understanding of the phenomenon being studied (Charmaz, 2014). Constructivist grounded theory studies typically examine a phenomenon and aim to generate a theory to explain that phenomenon, examples include: *A constructivist grounded theory study to explore compassion through the perception of individuals who have experienced nursing care* (Straughair et al, 2019); *Searching for meaning: A grounded theory of family resilience in adult ICU* (Wong et al, 2019); and *Insights on compassion and patient-centred nursing in intensive care: A constructivist grounded theory* (Jakimowicz et al, 2018). Researchers using this methodology begin with inductive logic, subject their data to rigorous comparative analysis with resultant theory emerging from participants' data; emerging theory is said to be grounded in the participants' data (Parahoo, 2014). The emphasis of a constructivist grounded theory study in the healthcare setting is on the truth as understood by an individual or group who share a particular experience (Charmaz, 2014), allowing for the creation of theory that is grounded in the everyday reality of clinical practice (Elliot and Lazenbatt, 2005). Charmaz's (2006) constructivist approach views the world as socially constructed, proposing a view of reality that seeks to represent the meanings placed on the reality of both the researcher and the research participants. In constructivist grounded theory the researcher and participants interact during data collection, co-constructing new knowledge through the experiences and views of the participants and the lens of the researcher's interpretation of the raw data (Charmaz, 2006). A pathway to help novice researchers navigate the research process in constructivist grounded theory has been described (Charmaz, 2014), and is outlined in Figure 4.1 below. These phases are not linear, rather the researcher moves freely upwards and downwards between the phases.

Constructivist grounded theorists acknowledge that the research process occurs under pre-existing conditions and is influenced by the researchers' prior experiences, perspectives and geographical location (Charmaz, 2014). They take a reflexive stance toward the research process and its end products. In the words of Charmaz (2014; p. 240) "Conducting and writing research are not neutral acts". She goes on to advise that we must aim to avoid importing our assumed values and beliefs into the research process. This can be done by engaging in reflexivity throughout the process, by reflecting on and examining how our life experiences and assumptions have influenced our interpretation of the data, adding to the transparency of the study. Furthermore, this research study will meet the criteria for patient-

(including parents and family) orientated research as outlined by Kaur and Pluye (2019): (a) it involves patients and families as partners in the research process (b) it addresses outcomes deemed important by patients and families; and/or (c) the findings will contribute to at least one of the following: patient health and experiences, health professionals' practice, and/or healthcare services and policies.

Figure 4.1: Pathway for a grounded theory research study (modified from Charmaz, 2014; p. 18).



This constructivist philosophy as described by Charmaz (2006; 2014) is congruent with my worldview. I believe that the explanatory theory must emerge from, and be grounded in, the participants' data. Implicit in this belief is the role I have as a researcher in seeking a non-judgemental understanding of the phenomenon being explored, by remaining open to all possibilities within the data. When collecting and analysing data I was conscious of remaining open and non-judgemental at all times. Furthermore, I believe that my personal and professional experiences have influenced my view of reality, my understanding of how knowledge is created and how life experiences are viewed. Hence, my interpretation of the data was influenced by my personal and professional experiences to date, and these influences contributed to the resultant theory. Each individual participant's description of their experiences of being in hospital made a valuable contribution to the explanatory theory that emerged. The resultant theory can then be said to have been co-constructed by the participants and I. The findings of this research explain what it is like to be in hospital for children aged nine to 16 years and their parents in Dublin. The experience may be different for children and their parents in another hospital in another country, or indeed in another hospital in Ireland.

The data, data analysis and emergent theory were contextualised to the situation where the data were collected and where the participants experienced the phenomenon (Charmaz, 2006). According to Charmaz (2014; p. 17) the theory resulting from a constructivist grounded theory study is "an interpretive portrayal of the studied world, not an exact picture of it". The participants' views and experiences and the final theory resulting from this research are constructions of the participants' reality, not an exact picture of what it is like for a child/adolescent and their parent to be in hospital in Ireland. The findings can be transferred to other similar settings if the reader deems the research setting is similar enough to their setting.

4.1.5.3.4 Key features of constructivist grounded theory

According to Charmaz (2014) concurrent data collection and analysis using inductive and abductive logic, constant comparative analysis, coding and categorisation of data, memo-writing and theoretical sampling are key features in constructivist grounded theory.

Concurrent data gathering and analysis: the researcher gathers and analyses data simultaneously, coding and categorising the data as they emerge. Abstract analytic categories are developed inductively through systematic data analysis. Then the researcher considers all possible explanations for the data, checks these possibilities with further data before arriving at the most reasonable explanation. The researcher returns to the data as needed and continues to gather data until theoretical saturation occurs, when no new insights emerge about the identified categories (Charmaz, 2014).

Constant comparison analysis: the data analysis process that is central in grounded theory. It involves the researcher constantly comparing data with data, codes with codes, codes with categories and categories with categories. The researcher starts with line-by-line *in vivo* coding, using the participants' own language and creating codes freely. Initial codes are then collapsed into higher level categories at increasing levels of abstraction during focused coding. Constant comparative analysis allows consistencies and variations within the data to be discovered. In this way, the key concern of the participants emerges to form the core category and its properties can be defined. Finally the researcher engages with theoretical coding as he/she identifies relationships among substantive codes. Theoretical codes describe how two substantive codes relate to each other (Charmaz, 2014).

Coding and categorisation of data: In constructivist grounded theory data analysis begins as soon as data are collected, and comprises of three phases of coding which are referred to as initial, focused and theoretical coding (Charmaz, 2014). The process of establishing codes and categories is akin to the researcher having an intense dialogue with the data, in the process of building theory (Basit, 2003).

Memo-writing: Writing memos is an important feature of grounded theory and continues throughout the research process. Memo-writing involves writing notes to self, recording one's thoughts, ideas and ongoing analysis of the data throughout the data analysis process (Charmaz, 2014). Memos can provide an audit trail of analytical decisions the researcher has made about the data and enhance the validity of the research (Charmaz, 2014). Memos also help the researcher to follow leads in the data and identify possible sources of further data.

Theoretical sampling: Data analysis guides subsequent data collection and interview questions, so that themes explored in previous interviews are developed in more detail in future interviews. This technique, known as theoretical sampling, prompts the researcher to explore emerging categories in more detail with future participants by asking targeted probing questions to develop the categories until no new data emerge (Charmaz, 2014). Charmaz (2014; p. 26) describes this refocusing of data gathering in constructivist grounded theory as shortening the lens of a camera "to bring key scenes closer and closer into view".

These key features and how they were applied to this research project will be discussed in greater detail in Part Two of this chapter.

4.1.6 Conducting a literature review

Glaser (1992) advises to delay the literature review in order to avoid contaminating the researchers, or their emerging theory, with ideas from the existing research before data collection, advising that the related research should only be read after data collection. In contrast, Strauss and Corbin (1990) claim it is not possible to enter a research study without

bringing your professional and academic knowledge with you. They advise to critically engage with the literature throughout the research process, contending that it can help the researcher to identify what is important to the developing theory. Engaging with the literature in this way enhances theoretical sensitivity, by further developing the researcher's awareness of the nuances of the phenomenon being researched, and informs theoretical sampling (Strauss and Corbin, 1990). Thornberg (2012) talks about the literature being a source of inspiration, in what he calls informed grounded theory, where both the research process and the theory generated are informed by existing research. Dey (2003: p. 65) refers to this as the "difference between an open mind and an empty head." Charmaz (2014) comments that a lack of familiarity with the relevant literature is unlikely, claiming that researchers hold views and have knowledge which contribute to their decision to choose the research topic in the first place. Charmaz (2014; p. 308) advises to use the existing literature wisely, "without letting it stifle your creativity or strangle your theory", and to weave the literature throughout the research. She also advises that researchers need to be current about their research topic, that knowing the key terms used by the participants to describe their experiences will help form questions when developing the interview guide. Furthermore, using language the participants are familiar with during the interview conversations will help to put them at ease and encourage them to share their experiences in their own words (Charmaz, 2014). Ramalho *et al* (2015) contend that an awareness of the existing literature and actively working to ensure it is not imposed on the emerging theory is paramount to producing a theory that is grounded in the experiences of the participants. In a constructivist grounded theory study

"The researcher's influence - and through him/her that of the reviewed literature - is neither avoidable nor undesirable, but rather recognized and included in the analytic process." (Ramalho *et al*, 2015; p. 9).

A literature review was therefore conducted to obtain a comprehensive understanding of current knowledge on the topic (Cronin *et al*, 2008), to discover any gaps or inconsistencies in existing knowledge and identify areas for further research (Chiovitti and Piran, 2003; Munn *et al*, 2018). It also helped to situate the study in the broader context of current issues in nursing care of children in hospital internationally, thus providing a context for the study. The research problem and the aims and objectives were refined only after reviewing the literature. After the literature review was conducted, I explored possible research methodologies in order to identify which was most suitable for this study and constructivist grounded theory (Charmaz, 2006; 2014) was chosen because it promotes a fresh and open-minded approach when researching an existing concern and can be "used to gain new insights into old problems" (Corbin and Strauss, 2015; p. 11). Similar issues have been described by other researchers who did not decide on the research methodology until after

the literature review was conducted (McGhee *et al*, 2007). I was reminded again of Charmaz's (2014) advice to use the literature wisely throughout the research process. Strauss and Corbin (1998) also advise that being familiar with the literature before embarking on data collection and analysis can enhance theoretical sensitivity. In this case, it also informed the questions used to guide the interviews. Both Charmaz (2014) and Strauss and Corbin (1998) caution the researcher to avoid allowing knowledge of the literature suppress creativity during the data analysis stage. I remained acutely aware throughout this research study that I needed to remain open to the data and all possibilities within it, and avoid allowing my personal and professional experiences and my academic knowledge of the topic to influence data analysis. Performing a literature review requires finding a balance between reading enough to be aware of and understand possible factors that could influence the area of study, while still remaining open-minded to what the participants have to say.

4.1.7 Conclusion to Chapter Four - Part One

Part One of this chapter outlined in detail the researcher's philosophical underpinnings which are brought to the study, including my worldview and the events that led me to pursue this research topic. The rationale for the use of constructivist grounded theory (Charmaz, 2006; 2014) as the chosen methodology was given. It is a systematic and rigorous framework that allows for the flexible use of strategies for data collection and analysis. Constructivist grounded theory acknowledges subjectivity within every stage of the research process and recognises the importance of the participants' social context on their experience of the phenomenon under study. For me as researcher, both my personal experiences as a mother of a hospitalised child and the professional knowledge I had gained over many years practising as a children's nurse, influenced me in pursuing this research topic. My personal and professional understanding of being in hospital with a sick child provided me with starting point. The associated research methods and my reflections on the research process will be described in detail in Part Two of this chapter.

4.2 Chapter Four - Part Two – Research methods

4.2.1 Introduction

In Part Two of this chapter I will outline the procedures and techniques, collectively referred to as methods, used to address the research problem and achieve the aim and objectives of the study. Research methods are described as strategies, techniques and procedures for gathering and analysing data (Corbin and Strauss, 2015). They can be thought of as the detailed master plan of the research, which explains how the study was conducted, showing how all the major strategies, techniques and procedures worked together to address the research problem. There are many stages involved in qualitative research, from gaining ethical approval, accessing the research site, sampling, data collection, data analysis and interpretation of the research findings (Creswell and Creswell, 2018). I used these techniques as a set of guidelines rather than as rigid rules, and applied them in a flexible manner as advised by Charmaz (2014), keeping within the general guidelines of constructivist grounded theory. I tried to present the methods in the order that they occurred, however many of these stages occur simultaneously with the researcher moving back and forth through the stages throughout the research process. There was considerable multi-tasking as the research journey unfolded. This can lead to what appears to be a disordered presentation of the methods, which may be confusing. Part Two of this chapter needs to be read in full, before a complete understanding of the methods used can be reached.

4.2.2 Ethical principles when conducting research

Professional and ethical practice standards are as important in research practice as they are in clinical practice (Sally, 2014). The expected standard in clinical practice of outweighing the benefits of care with any associated risks holds true for research practice also.

Data were collected through in-depth, semi-structured interviews with hospitalised children/adolescents and their parents, to gather information about their experiences and expectations of their roles while in hospital. Access to children/adolescents in hospital and their parents was granted through the hospital Research Ethics Committee. A key role of Research Ethics Committees is to protect participants from possible risk and harm as a result of participation, by ensuring that the proposed research study meets the ethical standards as described in professional guidelines and codes of practice (Gelling *et al*, 2021). The research proposal presented to the Research Ethics Committee demonstrated that the new knowledge generated from this research will benefit the participants. Age-appropriate Participant Information Leaflets for children aged nine to 12 years, for adolescents aged 13 to 16 years and for parents were designed with associated age-appropriate Informed

Assent/ Consent Forms. An interview guide for each cohort was also developed. These documents, together with an outline of the research study, were presented at the Research Ethics Committee and reviewed at the meeting on 16th July 2019. See Appendix 13 for completed Hospital Research Ethics application and approval.

This research study adhered to the ethical principles and professional guidance outlined in the *Ethical Conduct in Research: Professional Guidance* (Nursing and Midwifery Board of Ireland, 2015) and in *Guidance for developing ethical research projects involving children* (Department of Children and Youth Affairs, 2012). In addressing my responsibilities as a researcher to ensure that the participants come to no harm during the research process (Nursing and Midwifery Board of Ireland, 2015), a risk assessment was carried out to assess the potential risks to the participants, see Table 4.1. This assessment found that the risks to participants were minimal as a result of their participation in this study and was presented to the Hospital Research Ethics Committee. Mitigating measures are also described.

Table 4.1 Risk assessment

No.	Risk	Proposed mitigating measure	Comment
1	Inconvenience	This risk will be minimised by agreeing a time and place suitable to the child, adolescent and parent to conduct the interview.	
2	Loss of personal data	<p>In line with the Data Protection Act (2018) and best practice, only minimal personal data will be collected. Data to be collected will include: first name and surname of participants, age in years and months of the child and adolescent participants, age range of the parents, gender, ethnic origin and a personal email address for each participant.</p> <p>Prior to storing, personal data will be coded in such a way that only the Principal Investigator (PI) will recognise. Numbers and letters in code format will be used to record names and interview numbers. Hard copies of all data, including Assent/Consent Forms, will be stored securely in a locked cupboard in the PI's office which is also locked. Only the PI will have access to this locked cupboard. Electronic data will be coded and stored in the PI's personal profile on a TCD desktop PC which is password protected. Only the PI will have access to this profile.</p> <p>Interviews will be audio recorded. Recordings will be stored securely in the same manner as the personal data. Third party transcription services will not be used when transcribing recorded interviews, they will be transcribed in full by the PI and the content of the transcription agreed with the individual participant by email correspondence. Interview recordings will be retained in a secure cupboard in the PI's office until the successful completion of the PhD. At that stage they will be shredded and disposed of in a confidential waste disposal unit. Electronic data</p>	Personal data will be retained only until successful completion of the PhD, at that point it will be shredded and disposed of in a confidential waste disposal unit.

		will be deleted and interview recordings destroyed and disposed of in a confidential waste unit. The thesis and all reports and papers resulting from this research will be written up in an anonymised fashion, any risk of identification of participants will be removed in full.	
3	Psychological distress.	If a child, adolescent or parent becomes distressed during an interview they will be cared for in a sensitive manner and supported through their distress. They will be given an opportunity to end the interview early and withdraw from the study. They will be advised that the appropriate person(s) in the clinical area will be informed. Before leaving the child, adolescent or parent any necessary support will be put in place.	The appropriate person(s) in the clinical area will be the CNM and/or the nurse caring for the child/ adolescent.
4	Missing out on healthcare treatment	It will be made clear to the nurse in charge and to the nurse caring for the child/adolescent and parent before the interview takes place, that any healthcare assessment, intervention or treatment will take priority over the research interview. If the child/adolescent is needed for any healthcare intervention then this will be given priority and the interview will be suspended temporarily or ceased entirely.	

4.2.2.1 Conducting research with children

Special consideration is required when conducting research with vulnerable participants as they may be at increased risk of being wronged or harmed. Children are considered such a vulnerable group, and require special protection when conducting research (World Medical Association, 2013). Consequently, an application to the Faculty of Health Sciences (FHS) in Trinity College Dublin (TCD) was also required. This application was reviewed in October 2019, with final approval received in November 2019. See Appendix 14 for completed Research Ethics Application to FHS at TCD and associated documents.

The Helsinki Declaration (World Medical Association, 2013) states that medical research with children is justified only if it is relevant to their healthcare needs and cannot be carried out without their involvement. Additionally, child participants should benefit from the new knowledge generated as a result of the research, and the research must involve only minimal risk to them. The benefits to the participants of this study was demonstrated to outweigh any possible risks to them.

4.2.2.2 Involving children/adolescents in research

In healthcare practice there is increasing recognition of the rights of the child. The United Nations Convention on the Rights of the Child (UNCRC) (1989), to which Ireland is a signatory, refers specifically to a child's right to have their opinions heard and taken seriously on matters affecting them. A literature review revealed that parents want to participate actively in the care of their child in hospital, but the degree to which they wish to do so varies and needs to be negotiated between the nurse and the individual parent on an ongoing

basis (Watts *et al*, 2014; Coyne, 2013; Feeg *et al*, 2016; Curtis and Northcott, 2017). However, there is a paucity of robust evidence to support the contention that children wish to have their parents participate in their care in hospital, or if they wish to participate in their own care while in hospital. This is especially important for older children/adolescents, who are developing the skills of independence and autonomy, often wishing to be independent of their parents in many aspects of self-management, particularly in personal care. The voice of the child was noticeably absent from existing research. For this reason, it was considered imperative that further research must facilitate their participation in the research process, and listen to their voice. The findings must represent their views, experiences and expectations.

4.2.2.3 Who will benefit from this research?

The findings from this study will create the evidence needed to inform nursing care of future hospitalised children/adolescents and their parents/guardians that is child- and family-centred. The knowledge generated will support the delivery of nursing care that is truly reflective of the needs of hospitalised children/adolescents and their parents, leading to improvement in the quality of care provided to them.

4.2.2.4 Addressing risks to participants

4.2.2.4.1 Managing distress

Protecting participants from personal and social harm is the key aim of the ethical principles of all research. This research study adhered at all times, to the ethical principles and professional guidance as outlined by the Nursing and Midwifery Board of Ireland (2015) and by the Department of Children and Youth Affairs (2012). A potential risk to participants was identified as causing emotional or psychological distress during the interview, if the conversation re-awakened old feelings or memories which still distressed the participant.

Before agreeing to participate, I gave potential participants a general outline of how the interview discussion would be conducted, and an overview of the questions that would be asked. In this way any stress, or distress, that was likely to be experienced as a result of the research was minimised by ensuring potential participants were fully informed of what was involved in participating in the study before agreeing to take part. Additionally, support services were available to contact should a participant need such support. For this reason, interviews were scheduled when such services were available within the hospital, which meant that conducting interviews on Friday afternoons and during the weekend was avoided, as many of these services are closed at the weekend. In addition, I am a registered children's nurse with more than 30 years experience of communicating with children and their parents, often in difficult situations. This experience provided further reassurance that any psychological distress displayed by a participant during an interview, would be

recognised early and managed appropriately and sensitively, as outlined in the above risk assessment.

Furthermore, the participant was informed that he/she would be given the opportunity to end the interview immediately, if he/she so wished. The gatekeeper was key to identifying patients and parents who were more vulnerable to becoming distressed during the interview, if there was an existing psychological issue, and advising against inviting them to participate in the study, to avoid any further discomfort for them. The aim was to ensure the data collection process was not going to place undue burden on a child, adolescent or parent, given the context within which it was occurring. In qualitative research interviews, there is always a risk that the discussion may raise issues that have not been anticipated. I attempted to reduce this risk as much as possible, so that any remaining risk was justified within the context of the research aim, interview and research design. The use of an interview guide helped to focus the interview on the research topic by guiding the questioning, thus minimising this risk. More sensitive questions were included in the middle of the interview so that less sensitive and more “normal” conversation was expected towards the end of the interview. I always ensured the participant was not distressed or uncomfortable in any way before leaving the room, following completion of the interview. On one occasion while interviewing a mother, Mary, in a quiet room off the ward, she became distressed as she spoke about her son's chronic condition and the support they were receiving from the nursing and healthcare teams. I offered Mary the opportunity to end the interview, but she declined. Instead she took some time to compose herself and continued to the end of the interview. I remained with her for some time after the interview had ended and the recorder was turned off, to ensure she felt well again and was satisfied to return to her son's bedside. I asked if she needed the support of her nurse or a medical social worker, but again she declined. I explained that I would speak with the Clinical Nurse Manager (CNM) before leaving the clinical area to inform her of the distress Mary was experiencing, so that any further support could be provided if needed.

4.2.2.4.2 The steps to be taken if a child discloses he/she is at risk of harm

In line with *Children First: National Guidance for the Protection and Welfare of Children* (Department of Children and Youth Affairs, 2017), if a child or adolescent disclosed sensitive information during an interview indicating that he/she was being harmed or at risk of harm, either at home or elsewhere, it was agreed that the interview would be stopped. The disclosure would be discussed sensitively with the participant, and the obligation on my part to discuss the situation with the appropriate personnel within the hospital would be explained. The designated Child Safety Protection Officer in the hospital would be informed. This fact was made known to the parents in the appropriate participant information leaflet,

and reiterated verbally during the recruitment process. I attended education and training on child protection and am familiar with the national guidelines. Before collecting data, I also familiarised myself with the appropriate hospital policy on child safety and identified who held the post of the Child Safety Protection Officer within the hospital. I underwent a Garda vetting disclosure process prior to entering the field to collect data. This process was a requirement of the clinical site where data were collected, and provided evidence that I had no criminal record. At no time during the interviews did a child or adolescent disclose to me that they were being harmed or at risk of harm. Neither did I suspect that a child or adolescent was at risk of harm at home, at school or elsewhere.

4.2.2.4.3 The steps to be taken if a child requires nursing or medical attention

If a child or adolescent required nursing or medical attention during the interview it always took priority. Equally if a member of the healthcare team wanted to see a participant while an interview was in progress, it also took priority over the research interview. This was explained to the participant before the interview began. On a number of occasions the child required attention from nursing and/or medical staff when their intravenous infusion pump beeped, or it was time to receive medication. When this happened the interview was stopped to allow the intervention to be carried out. The participant was given the choice of discontinuing the interview altogether, or stopping it temporarily. All participants agreed to continue with the interview once the intervention was complete, and the participant was comfortable again. On one occasion while interviewing a father of a 13 year old girl, Owen, the physiotherapist arrived to perform post-operative physiotherapy for Owen's daughter. At this point the interview was suspended with the intention to complete it following physiotherapy. When I returned to the bedside to complete the interview about 30 minutes later, Owen had gone for something to eat and his daughter did not know what time he would be back. When Owen had not returned an hour later, I accepted that the interview was not going to resume and left the clinical area.

4.2.2.5 Managing risks to the researcher

The main risk to researchers when conducting research with children is the risk of legal action being brought against them through being placed in compromising situations. This risk is mitigated by ensuring that an appropriate and adequate level of internal or external support is available for the researcher before, during and after data collection (Social Research Association, 2021).

The physical safety of the researcher was not considered a significant risk during this study, since data gathering took place during normal working hours in a busy hospital setting, when there were many healthcare workers circulating in the clinical area who could be

called upon should help be needed. When interviewing on a one-to-one basis, there is always the risk of the researcher being placed in a compromising situation, with the possibility of being accused of improper behaviour. During this study the nurse-in-charge and the nurse caring for the child and parent were always informed when and where the interview was to take place. The expected end time was also discussed. Throughout the data collection process, I had the support of two senior research supervisors. Regular supervision meetings and email correspondence provided me with opportunities to reflect on the interviews and discuss any difficulties encountered. I did not encounter any personal risk during data collection for this study.

4.2.2.6 Managing the participants' personal data

Best practice when collecting personal data from participants is to include only minimal personal data (Government of Ireland, 2018).

Actions to mitigate against loss of participants' personal data included collecting only minimal personal data in the first place. Personal data were collected on the assent/consent forms, which included the child's/adolescent's name, age in years and months, their parent's name and a personal email address. Personal data collected from the parent participants included their name, their child's name, their child's age in years and months and a personal email address. Once collected this information was recorded on a word document and coded in such a way that only I could decipher. Each participant was given an individual identification code, for example Child interview 1 (male, nine years and 11 months), Adolescent interview 1 (female, 15 years and four months) and Parent interview 1 (mother). In this way the participant was not identifiable. For the purposes of reporting the findings, pseudonyms were used to replace participants' real names throughout this thesis, to maintain confidentiality and protect participants' anonymity. Hard copies of assent/consent forms were stored in a locked cupboard in my office, which was also locked. Electronic data, such as the transcribed interview data, were stored on my personal profile on a desktop computer which was password protected and kept in a locked office. It was agreed, and made known to the participants, that all personal data would be deleted or destroyed in a confidential waste disposal unit on successful completion of the PhD. It was also agreed, and the participants were informed, that all reports manuscripts and the thesis resulting from this research study will be written up in an anonymised fashion, ensuring that the risk of identifying participants was removed. No data protection issues arose during this study.

4.2.3 The research setting

The Hospital Research Ethics Committee granted approval for this research to be conducted with participants from four general in-patient clinical areas: clinical area A was a 22-bedded ward for children with orthopaedic and gastroenterology conditions; clinical area

B was a 22-bedded general medical ward; clinical area C was a 15-bedded surgical ward specialising in ear, nose and throat conditions and burns/plastic surgery, and clinical area D was a general surgical ward with 10 beds. All clinical areas accommodated children and adolescents between two and 16 years of age. This hospital is a large university teaching children's hospital in Dublin, Ireland. The mission statement of the hospital states that the hospital staff aim to promote and provide child-centred, research-led and learning informed healthcare, to the highest standards of safety and excellence, in partnership with each other, with children, young people and their families. Data gathering commenced in December 2019. As a result of the restrictions imposed due to the Coronavirus Disease 2019 (COVID-19) pandemic, data collection was interrupted during each of the national lockdowns. Data collection was completed in July 2021.

4.2.4 Inclusion/exclusion criteria

The inclusion criteria were informed by my belief that the quality of the research interview is dependent on the ability and willingness of the participants to articulate their experiences in their own words. Additionally, I speak only English and did not have access to the services of a translator, consequently I was unable to interview participants who did not speak English fluently, so fluency in English had to be an inclusion criterion. Inclusion criteria for children/adolescents were that they must be in-patients on one of the four designated clinical areas where data gathering was to take place, be aged between nine and 16 years of age, speak English fluently, be able to articulate their experiences and expectations of being in hospital and have a parent staying with them in hospital at the time of recruitment. Inclusion criteria for parent participants were that they must be parents of a hospitalised child/adolescent aged between nine and 16 years of age on one of the four designated clinical areas where data gathering was to take place, be fluent in English and be able to articulate their experiences and expectations of being in hospital with their child/adolescent.

4.2.5 The role of the gatekeeper

It is a requirement that gatekeepers protect and manage access to potential research participants for recruitment (Snowden and Young, 2017). The role of a gatekeeper in the context of healthcare research is to protect potential research participants who may be considered vulnerable, for example children, patients or their families (Lee, 2005). All those responsible for the health and safety of children and adolescents taking part in any research project must be assured that their safety, rights and interests are fully safeguarded during the research process. In the hospital setting not only the parents hold a position of responsibility towards children and adolescents, but also the healthcare professionals who are involved in their care. Consequently there are multiple gatekeepers to be navigated before the research interview takes place. Kars *et al* (2016) describe a number of

gatekeepers in the healthcare setting with whom the researcher must negotiate, including the Research Ethics Committee, organisational management, healthcare practitioners and relatives. It is noteworthy that the last person to negotiate with is the participant him/herself, either the child/adolescent or the parent, which may be an indication of a possible power imbalance (Coyne, 2010a). The Research Ethics Committee application procedures have been outlined above. This section will discuss the healthcare professional as the nominated gatekeeper within the clinical site where data were collected.

4.2.5.1 Gatekeeping in action

A gatekeeper is a nominated person from within the organisation where the participants are to be recruited from, and whose role and position in the organisation can vary. Gatekeepers have immediate access to the research participants and act as advisors to the researcher, in terms of the most appropriate clinical area to seek participants from on a given day.

Prior to applying for ethical approval to conduct this study, I contacted the Director of Nursing by email seeking a named person within the hospital to act as gatekeeper. The gatekeeper nominated for this research project was a busy senior nurse manager, with responsibility for clinical audit, practice and policy development. I visited the clinical site to meet with her and explain the research and recruitment process to her. She delegated local gatekeeping duties to the CNM and/or the Clinical Nurse Education Facilitator (CNEF) of each of the four clinical areas where the data were to be collected. The establishment of a good relationship with the gatekeepers before recruitment begins is vital to any successful recruitment strategy, so that the gatekeepers recognise the significance of the study to their practice, and are more likely to be supportive of it when recruiting participants (Snowden and Young, 2017). It is also important that the gatekeeper is aware of the inclusion and exclusion criteria which apply to the participants. In a study of gatekeeping behaviours it was identified that nurse gatekeepers can see “research as a burden for both themselves and the patient” or “as a low priority in relation to more pressing clinical issues.” (Snowden and Young, 2017, p.193).

Therefore, I arranged to meet with each individual CNM and/or CNEF before recruitment began. Having outlined the research to them, I gave them a copy of each of the Participant Information Leaflets and Assent/Consent Forms, and a summary of the research to date. During this first meeting with the local gatekeepers I explained the importance of the study to their clinical practice and to the healthcare experience of their patients and families. The CNMs/CNEFs agreed to inform their nursing colleagues about the research at forthcoming team meetings, and advise them that I would be visiting the clinical area in the coming weeks to interview patients and parents. Participant inclusion and exclusion criteria were discussed in detail at this meeting also.

The CNMs/CNEFs as local gatekeepers, advised me of the potential participants and the best times to approach them. They were also key to protecting potential participants from any undue burden of participating in the study. If they considered the child or adolescent was either too sick or vulnerable to participate in the interview because of his/her health, emotional or family situation, they advised me not to invite them to participate in the interview on that day. This screening process was also applied when recruiting parents to participate in the study. When such a situation arose, it was agreed that I would return on another day later in the week to invite them to participate. However, this plan did not always work in my favour, because either the child had been discharged home or the parent was not with the child/adolescent when I returned on another day. This is not surprising given the average length of hospital stay for a child/adolescent is now approximately 72 hours (Healthcare Pricing Office, 2022). With early discharge and care closer to home being key targets of the health services, the child/adolescent is discharged home as soon as his/her condition stabilises and he/she begins to feel better. For those children whose hospital stay is prolonged, it is possible that they may have become more comfortable in the hospital, and are content to stay unaccompanied for a few hours, while their parent takes a break from the bedside, either to take a walk outdoors or to meet a friend for coffee. The local gatekeeper and I ensured that the children/adolescents invited to participate in the study met the inclusion criteria. Being aware that gatekeeping was additional to their already busy workload, I always attempted to cause as little disruption as possible to the working day of the clinical staff and the healthcare experience of the child/adolescent and parent.

Screening of potential participants by gatekeepers is acknowledged to be subjective because it is dependent on the gatekeeper's clinical knowledge and judgement, as well as on their personal belief of the importance of the research and their role in “protecting” or “promoting” children and parents to participate in research (Coyne, 2010a). Some children/adolescents and parents may have been “protected” from taking part in the study without sound rationale. This limitation can be difficult to overcome in light of the position of power the gatekeeper holds in the clinical area. By discussing the importance of the outcomes of the research for patients, their families and for children's nurses with the gatekeepers before the recruitment process, I was attempting to promote the inclusion of as many children and parents as possible, to ensure they were all given an opportunity to have their voice heard and thus minimise the subjective screening of potential participants by the gatekeepers.

4.2.5.2 The relationship between the gatekeeper and potential participants

In managing the recruitment process, researchers need to consider the relationship between the researcher, the gatekeeper and the potential participants (Coyne, 2010b). The power dimension associated with this relationship may result in potential participants feeling

under pressure to agree to take part in research. While the senior nurse manager nominated as gatekeeper by the Director of Nursing did not know the potential participants in any personal or professional way, the CNM/CNEF of the clinical area where the data were being gathered had a professional relationship with the child/adolescent and parent. Consequently, it was possible that the relationship between the CNM/CNEF and the patients and parents may have been associated with a power dimension, resulting in potential participants feeling unable to refuse to participate, and the true voluntary nature of the consent process being jeopardised. Wilkinson and Wilkinson (2018) argue that these power differentials may never be fully eliminated, and advise that they must be minimised where possible. Another potential problem is that gatekeepers may not fully explain the research to potential participants, so the initial decision to take part, or not, in a study may not be based on complete information.

In order to manage both these situations, it was agreed that once the CNM/CNEF identified all potential participants in the clinical area to me, I approached them to explain the research and invite them to take part, ensuring that they fully understood what was involved. I, as primary researcher, did not know the patient or parent in any way prior to meeting them to invite them to participate. In this way potential participants were not put in a position where they felt obliged to participate because of a relationship of power with the CNM/CNEF, they were also fully informed about what was involved before assenting/consenting to take part. This process ensured the participants were fully informed before voluntary assent/consent was sought and the study commenced. I facilitated ongoing assent/consent throughout the interview conversation. Withdrawal from the study at any stage was also facilitated, without judgement and with no repercussions to the participants. While no participants asked to withdraw from the process after giving consent, a number of potential participants took a relevant Participant Information Leaflet and were considering participating. When I returned a number of hours later to check if they were going to participate, they declined to take part. A reason for doing so was never sought, I always respected their decision and wished them well. I also reassured them that there would be no repercussions for having decided not to participate, either for them or for their child, now or in the future.

4.2.6 Recruitment of participants

4.2.6.1 Voluntary participation and informed consent

Informed assent/consent is based on the principle that information is given in language that the recipient understands, and that he/she understands any risks or benefits associated with taking part in the study (Water, 2018). Research participants should agree to participate voluntarily on the basis of adequate information. This is not a once off decision, but an ongoing process. It is best practice that even if participants have given consent at the beginning of the process, they are entitled to decline to answer any particular questions

without giving a reason, and are entitled to change their mind and withdraw from the study at any point, again without giving a reason. They can ask for their personal data to be removed from the study where practical (Government of Ireland, 2018). For children and adolescents under 16 years of age, it is necessary to obtain their assent and then to gain consent from their parent/guardian (National Consent Advisory Group, Health Service Executive (HSE), 2019). In research the child's/adolescent's wishes should be paramount, therefore if a child/ adolescent does not assent to participate, consent from the parent/guardian cannot be considered valid.

4.2.6.2 Gaining consent from parents

The Research and Ethics Committees in both the hospital and university settings considered the process by which assent/consent was to be obtained, including who asks for it, as well as any materials given to participants to support the process. Participant Information Leaflets about the research were developed, which were tailored to each participant group using age-appropriate language and in easily understandable format, rather than technical terms and healthcare jargon. These information leaflets included information about the purpose of the research and what would be expected of the potential participant if they were to agree to take part. For this study three versions of the Participant Information Leaflet were necessary due to the wide variety of ages of the potential participants, and expected cognitive abilities of those who were to be invited to participate - one leaflet for children aged nine to 12 years of age; one for adolescents aged 13 to 16 years of age and one for parents, see Appendix 15. Similarly, assent/consent forms were developed for each of the three potential participant groups, using the same criteria, see Appendix 16.

It was made clear to participants that by signing an assent/consent form, they should not feel "obliged" to continue to take part or answer particular questions, if they are not comfortable doing so. I ensured that voluntary, informed written consent did not compromise the process of ongoing consent by seeking reassurance during the interview that the participants were comfortable to continue. Potential participants were informed, both verbally and in writing that they could withdraw at any time without any repercussions to them or their family member. They were also given an opportunity to ask questions and seek clarification about any aspect of the study they were unclear about. Their right to refuse to participate in the study was also explained. Parents were reassured that their decision not to participate would be fully respected and would not affect the care their child received in any way, now or in the future.

In order to participate, the parent had to have a child/adolescent as an in-patient in hospital at the time of the interview. As a result of early discharge, the average length of stay for a child in hospital is 72 hours (Healthcare Pricing Office, 2022). It is recognised that obtaining

informed consent includes giving potential participants a reasonable period of time to reflect and decide whether they will take part in the research (Morrow, 2008; National Consent Advisory Group, HSE, 2019). The Research and Ethics Committee at both the clinical site and the university agreed that allowing such time for reflection would, in many cases, preclude children/adolescents and their parents from taking part in the study. Because of the minimal risk of participating in this research, it was agreed that a reflection period of up to 24 hours was sufficient for potential participants to consider the information, before written informed consent was sought. If a potential participant wished to reflect for a longer period, then that could be facilitated on an individual basis. I obtained consent from the participants on the day of the interview. I gave all potential participants approximately three hours to consider if they wanted to participate. No child, adolescent or parent asked for more time to consider their participation, they decided after the three-hour reflection period to participate or not.

4.2.6.3 Gaining assent from children

Children under the age of 16 years are not allowed to give consent for participation in research themselves by Irish law (National Consent Advisory Group, HSE, 2019), informed written consent must be sought from their parent or legal guardian. It is considered best practice to involve the child or young person in the consent process, including them in any discussion about their participation, and seeking their assent. When a potential research participant cannot give informed consent him/herself, but is considered capable of giving assent, the researcher should seek their assent in addition to the consent of their legal guardian (World Medical Association, 2013; National Consent Advisory Group, HSE, 2019). Both the Declaration of Helsinki (World Medical Association, 2013) and the National Consent Policy (National Consent Advisory Group, HSE, 2019) advise that the potential participant's dissent should also be respected.

With this in mind, parents were asked to read the appropriate Participant Information Leaflet with all potential child participants, following which they were given the opportunity to ask any questions they may have. Adolescents were asked to read the appropriate Participant Information Leaflet themselves and afterwards given the opportunity to ask questions. In both cases the parent was encouraged to be present with the child/adolescent when they were reading the leaflet as recommended in the National Consent Policy (National Consent Advisory Group, HSE, 2019). The parent's presence provides an opportunity for them to act as an advocate for the child/adolescent and provide them with a degree of security, comfort and support. For all children/adolescents who agreed to participate in this study, written informed assent was obtained. The assent form was signed by the child/adolescent in the presence of one parent, and then co-signed by that parent. In this way they are given the opportunity to make their own decisions, and to confirm that they are willing to

participate in the research. In the event that a parent agreed for their child to participate and the child did not agree, the child's dissent always over-rode the parent's agreement.

4.2.7 The interview guide

The interview guide is a set of open-ended questions focused on the research topic, which guides the interview and promotes the development of the emergent theory (Charmaz, 2014). It acts as a prompt to the interviewer on what questions to ask and in what order. It is not intended to prevent participants from talking freely to express their own experiences and share their perspectives (Parahoo, 2014). Charmaz (2014) advises the novice researcher that the interview guide should aim to elicit the participants' views and experiences, not those of the researcher, and thus promote the collection of richer data through the use of probing questions.

Initially a single interview guide was developed using plain English to guide me in my line of questioning. However, on reflection following the first round of interviews I deemed it necessary to develop three interview guides appropriate to each cohort of participants (children, adolescents and parents), using plain English, age-appropriate language and everyday terms that were familiar to the participants, see Appendix 17 for Version one of the interview guide. The questions included in the interview guide were informed by a concept analysis, a literature review, the research question, my prior professional knowledge on the topic and expert advice from academic supervisors. While developing an interview guide, I reflected on the language I was going to use and any assumptions I may inadvertently bring to the interview process, in an effort to minimise them. When formulating questions to ask a child or young person, it is important that the questions are appropriate for their developmental age. My extensive experience as a children's nurse together with my reading on the topic, helped me to be familiar with the language used to describe the topic for adolescents and children. Charmaz (2014) contends that knowing the key terms to use when developing the interview guide can help to put participants at ease. Broad open-ended questions, which were aligned with the research aim and objectives, were devised to elicit the experiences and views of the participants. I began with broad "what?" and "why?" questions, which encouraged the participant to talk freely (Moser and Korstjens, 2018). Once I felt that the participant had settled into the interview and appeared at ease, I proceeded with "how?" questions. I allowed the tone and pace of the interview to be set by the participants, as advised by Charmaz (2014).

The original interview guides were reviewed and agreed by two experienced research supervisors. I used them flexibly so that leads could be followed as they arose, by asking additional questions for clarification purposes, to explore a topic which I felt might enrich the findings. In order to avoid the interview turning into a rigid questions and answers session, I did not always follow the order of the original questions exactly, rather I aimed to

hold a conversation that was as near to normal as possible, as advised by (Parahoo, 2014). At all times I attempted to maintain a relaxed approach to the interview conversation, in order to encourage the participants to talk openly about their experiences and expectations. As a novice researcher the interview guides kept me focused on the topic and on track. Conducting the interviews without such a guide would have added to my anxiety about the situation, and may have compromised the quality of the interviews. Interviewing without an interview guide is not recommended, especially for novice researchers (Charmaz, 2014).

The interview guides also helped me to guide the participants and keep them focused. In the event that a participant veers off track, Creswell and Creswell (2018) advise that the interview guide can be used to help re-focus the line of questioning. One mother, Iris, went off track during the interview when she spoke about the financial difficulties she was experiencing as a result of being in hospital with her teenage daughter for more than six weeks. I used the interview guide to re-focus my line of questioning with some degree of success. Later that evening I noted in my research journal that she had gone off track frequently during the interview and I reflected on my attempts to re-focus the interview. Such reflections helped me to enhance my use of the interview guide and develop my interview skills.

4.2.7.1 Revising the interview guides

As the study progressed the interview guides were reviewed and revised following each round of data collection. With each revision, they became more focused as new questions were added to clarify and gain deeper insights into the emerging codes and categories following initial coding of earlier interview data. During each interview I listened for leads and cues that added to the richness of the data. Following preliminary data analysis, the interview guides were reviewed, and sometimes revised with additional questions and probes added, in an attempt to stimulate discussion with the next participants around key emerging issues identified in earlier data analysis. Analysis of the data gleaned from these additional probing questions add to the development of the grounded theory (Charmaz, 2014). The interview guide evolved in this way following data analysis of each interview transcript throughout the data collection phase, in keeping with constant comparison analysis, ongoing data analysis and emerging preliminary codes. This practice is reflective of the iterative nature of data gathering and analysis in constructivist grounded theory research. Each revision of the interview guides for each cohort of participants is presented in Appendix 18.

I also continued to follow up on cues and leads that I picked up on from the participants. It is important to acknowledge that the interview guide was reflective of the emerging codes and categories and my attempt to uncover further information that would illuminate the participants' concerns. It was not an attempt to lead the participant in any way. For example

the category “Parents advocating for their child” began to emerge following initial coding of interviews with parents in Rounds One and Two. A review of the interview guide led to the inclusion of the question “How much have the nurses discussed (negotiated) with you what you can do and what is best left for the nurses to do for your son/daughter while you are in hospital with him/her?” I believed this would shed light on how the parents advocated for their child in the context of seeking to help them.

This flexibility allowed me to follow-up on concepts derived during analysis of previous interview data (Corbin and Strauss, 2015). It also allowed me to ask more probing questions to pursue a line of inquiry that is recurring following analysis of earlier data or to drop false leads if I believed they were not recurring. Preliminary conclusions made following analysis of early interview data, informed the revision of the interview guides. These preliminary conclusions were challenged with deeper more focused questioning.

4.2.8 Purposeful sampling

The size of the sample, and sampling techniques, in a research study is guided by the methodology (Parahoo, 2014). When planning a sampling strategy, qualitative researchers are advised to be creative, the sampling strategy must aim to be responsive to real-world conditions and meet the needs of the study (Coyne, 1997). In constructivist grounded theory purposeful sampling is used initially to identify participants who can provide rich, focused insights into the phenomenon being studied and who can contribute typical and diverse views and opinions (Appleton and King, 1997; Charmaz, 2014; Cleary *et al* (2014).

Posters/flyers notified potential participants of the research two weeks prior to commencement of the study. When I visited a clinical area to recruit participants, I approached the CNM/CNEF on duty and together we reviewed the list of all children/adolescents who were in-patients on the ward. We identified all those patients who met the inclusion criteria and whom the CNM/CNEF believed would not suffer unnecessarily as a result of taking part in the interview. Then I approached all potential participants who met the inclusion criteria and invited them to take part in the study. Taking part meant participating in an individual face-to-face interview conducted in the hospital, at a time that suited the participant.

The CNM/CNEF advised me about potential participants who they considered to be articulate and who had been in hospital for more than two nights because we believed the longer length of time in hospital would add to their knowledge and experience. More articulate participants are expected to talk about their experiences fluently and clearly so that the data gathered would be rich and valuable (Cleary *et al*, 2014). As advised by Charmaz (2014) and Parahoo (2014) I attempted to seek diverse views and opinions by searching for a diverse participant group, for example participants of varying age and

gender and who were not originally Irish. This proved difficult as most of the patients were of Irish origin, those who were of non-Irish origin often declined to participate.

The aim of this sampling strategy was to be as inclusive as possible of varied family types, from varied social and cultural backgrounds. By purposefully selecting participants in this way, it was possible to include children/adolescents of varied ages and from varied cultural backgrounds in the study. It also ensured that a mix of children/adolescents with acute and chronic conditions were recruited, as experiences may vary as a result of repeated hospitalisation and engagement with healthcare professionals. Parents from varied cultural backgrounds were also purposefully selected and invited to take part. This initial sample was selected to provide rich data on the topic, and led to theoretical sampling.

4.2.9 Data collection methods

In grounded theory data are most frequently collected through interviews and/or observations (Corbin and Strauss, 2015). Interviewing people whose experiences can shine a light on the phenomena under study is the main tool for gathering data in constructivist grounded theory studies (Charmaz, 2014).

The data for this research were collected through in-depth semi-structured interviews with pre-teenage children aged nine to 12 years and teenagers aged 13 to 16 years. Parents of hospitalised children were also interviewed. In this way their experiences and expectations were explored. It is believed that children from nine years of age are likely to have the cognitive ability to participate in the interview process, and the ability to articulate their experiences verbally (Coyne, 2007). In-depth semi-structured interviews with hospitalised children, adolescents and their parents was considered the best approach to gathering the rich data necessary to provide the diverse perspectives needed to develop a theory to explain the concept of child and parental involvement in care in hospital. Semi-structured interviews which are well facilitated and focus on the topic to be explored, allow the participants to express their experiences and insights in a safe and non-threatening space (Charmaz, 2014).

4.2.9.1 Choosing the location of the interview

In order to minimise any risk of distress to the participant and to encourage participation, interviews took place at a time and venue chosen by the participant. Interviews with parents were conducted at the hospital, in the clinical area where their child/adolescent was admitted. Initially this was because the parent did not want to stray too far from his/her sick child/adolescent. The clinical staff facilitated us in a quiet, comfortable room on the ward, free from interruptions, usually either a meeting room or the CNM's office. I believed that while it was important that the interview took place in a quiet space, with no disturbances, the parent needed to be easily accessible to their child if needed. In this way parents were

relaxed and were encouraged to share their experiences with me. However, later it became necessary to remain on the ward because of COVID-19 restrictions, which advised parents and children not to leave the clinical area unnecessarily.

Children/adolescents who were cared for in a single room (n=16) were interviewed in their room. Children/adolescents who were cared for in a shared room (n=7) were, where possible, interviewed in a quiet room on the clinical area. Where this was not possible they were interviewed at their bedside (n=4), which was not ideal as the shared room is a noisy space and there was always the possibility of being interrupted. Nonetheless, four interviews were conducted in such conditions. When interviews were conducted in a shared room the curtains were drawn to provide some degree of privacy and avoid distraction. The data gleaned from such interviews were not considered to be of poorer quality than the data from interviews held in either single rooms or a quiet room in the clinical area.

4.2.9.2 Interviewing parents

The role of the interviewer, who is often a stranger to the participant, is to listen carefully, encourage, observe sensitively and learn (Charmaz, 2014). It does not include educating, correcting or advising the participant if he/she says something that the researcher does not agree with.

When conducting interviews, I paid careful attention to my social skills like listening actively, developing a rapport of trust to promote engagement and displaying empathy. I used soft, age-appropriate language like "When you mentioned can tell me more about how that made you feel?" "That's an interesting point, can you describe for me what you meant by?" in an effort to encourage the participants to talk at their own pace and share their valuable insights about their experiences with me. At all times I avoided interrogating the participants, instead I tried to respond in ways that encouraged them to elaborate and tell their story in their own words, so that their perspective on the topic would be represented in the findings. The skills of courtesy and respect were always part of my everyday practice when I was working as a clinical children's nurse. I listened actively at all times to my patients, their parents and to my professional colleagues. Developing a rapport with the child and family, as well as practicing empathy, are essential to the practice of compassionate nursing care. These skills remain my personal philosophy in everyday social and professional interactions. While interviewing parents I listened attentively and respectfully to what they had to say, remembering that they were willingly, and without recompense, giving me the gift of their time and sharing their experiences with me for the benefit of other children and their families. In return, Donalek (2005) advises the researcher to respect that gift and use it responsibly, so that others may benefit from the participants' experiences. Before taking my leave of the participants I always thanked them for their

time, for sharing their experiences with me and for their contribution to improving the experience of hospitalisation for future children and their parents.

I kept the interview questions brief and unambiguous as advised by Donalek (2005), and showed I was listening actively by non-verbal cues, such as leaning in attentively, holding an open posture, maintaining eye contact, nodding, using phrases like “uh huh” and “I see”, and summarising what the participant said in his/her own words as advised by DeJonckheere and Vaughn (2019). According to Charmaz (2014) the researcher directs the beginning of the interview, while the participants direct the ongoing discussion due to its semi-structured nature. I was conscious of my role as researcher and attempted at all times to speak less than the participants during the interviews. I was alert for early signs of distress, and was prepared to either consider an alternative line of questioning or cease the interview if necessary. This happened on one occasion while interviewing Mary (mother of a 14 year old boy) and was dealt with sensitively and respectfully, as described earlier. Consistent with constructivist grounded theory, I pursued recurring ideas, leads and issues as they emerged during the interview, in order “to learn what is happening” (Charmaz, 2014; p. 85). I used probing questions to explore emerging concepts in greater depth. Before ending each interview I asked the participants if they wished to add something else that they felt was relevant to the conversation. This I believed gave them an opportunity to add something that was not captured earlier in the conversation. Some parents used this question as an opportunity to express their dissatisfaction at the facilities afforded to them while in hospital with their sick child, as Jackie said after spending five nights in hospital with her son:

“Em, I suppose the only thing I can think of is the [sleeping] mats on the floor, they're not very comfortable, and they are great and you're so delighted to get them on the first or second night. But by the end of the week you do ... like my back is killing me, my shoulders are killing me,”

4.2.9.3 Interviewing children

The UNCRC (1989) Article 12 states that all children have the right to express their views freely in all matters affecting them, and that their views should be given due attention. Coyne and Carter (2018) assert that the best people to provide information on children’s perspectives are the children themselves, advising that sensitivity and creativity are needed to maximise their engagement and participation in the research process, and their contribution to the research findings.

I recognise that listening to children’s and adolescents’ own perspectives in order to meaningfully understand their lives is best practice in research. Children were included as participants in this research study so that their perspectives were captured through their

own voice, rather than by proxy through that of their parents/guardians. In this way children and adolescents provided first-hand contributions to the findings of this study and to the care of children in hospital. Far too often children's perspectives on issues that are important to them are captured through their parents' voices, who are thought to know what is best for their child. In order to provide services that are child and adolescent friendly, and responsive to their needs, it is essential to elicit their views and experiences (Coyne, 2007).

One-to-one interviews were chosen in preference to focus group interviews, as they encourage more detailed conversation when discussing personal experiences with children and can elicit rich data (Coyne *et al*, 2009). Children who are naturally shy may not speak in a focus group, while those who are naturally extroverted may dominate the conversation. I attempted to avoid this situation through one-to-one interviews. Where possible interviews with children/adolescents were conducted in a quiet room on the ward or at the bedside, without the presence of their parent. I always offered the parent the opportunity to go out for a walk or for a coffee. There is evidence that when children are interviewed alone they may share their opinions more freely, than when they are interviewed in the presence of their parent (Gardner and Randall, 2012).

However, it was not always possible to interview the child on his/her own, sometimes the parent requested to remain in the room for a variety of reasons, such as to protect the child from any potential distress. In one case a nine year old girl, Dora, asked that her mother remain in the room while the interview was being conducted. During Rounds Two, Three and Four of data gathering, COVID-19 restrictions were in place, so parents were asked not to walk around the hospital unnecessarily. During this time the parents' rest room on each clinical area was closed to avoid unplanned congregations, which increased the risk of spreading the virus. For these reasons most children/adolescents (15 of 23 (65%)) were interviewed with their parent present. This could be considered a limitation of the study.

As with parents, before ending the interview I always asked the children and adolescents if they wanted to add something else that they thought was relevant before turning off the recorder. Some participants took this opportunity to express their appreciation of the nursing staff, for example Brian, aged 13 years replied:

“Not really, they’ve [the nurses] been a great support and helped a lot over the week, eh they’ve been always smiling and there’s just never been a frown on any of them, ... It’s hard to be happy, but seeing the nurses with a smile on their faces all the time is always nice to see and you will smile if you see the nurses smile as well.”

4.2.9.4 Developing a rapport with the child/adolescent

In conducting a research interview with children, the standards that apply to interviewing adults also apply, these include developing a relaxed rapport, using clear, age-appropriate language, using short, clear, open-ended questions, listening attentively and using soft verbal prompts to probe an issue (Ponizovsky *et al*, 2019). Children will share their experiences more freely when they are at ease with the researcher, in a relaxed environment (Coyne and Carter, 2018). Interviewing children requires skill, expertise and patience to put the child/adolescent at ease, develop a relaxed environment and glean most from the interview conversation (Coyne *et al*, 2009).

In an effort to prevent the child/adolescent from feeling like the interview was a test, before the interview began I informed them that there were no right or wrong answers, that I was looking for their opinions. Answering with “I don't know” or “I'm not sure” was perfectly fine. I made it clear that they could stop and ask me to clarify anything at any stage, if they did not understand what I had said. I explained that if I asked a question that they did not want to answer, then that was OK. I used play and informal “chat” at this time as a strategy to help put the child/adolescent at ease, establish a rapport and promote a free-flowing conversation. During these “chats” I spoke about my daughter if she was of a similar age to the participant, sometimes I talked about our pet dog and asked if they had a pet at home, or asked about what sports they played, their hobbies or their favourite music artist. I always asked permission to begin the interview and the audio recorder. Despite my best efforts, there were some occasions when the participant was slow to settle and gave short responses when I began the interview. This mainly happened with younger children, for example a nine year old girl who frequently looked to her mother for reassurance during the interview, suggesting that she was afraid she may have been giving the “wrong” answer. I also avoided following every answer with another question, instead I asked the child to explain in greater detail or simply acknowledged their response by paraphrasing what they had said. In later interviews, the strategic use of gentle targeted probing questions to support the child/adolescent to explain their experiences of being in hospital in his/her own words, was an important skill I developed as interviewing and data gathering continued.

Interviews with children and adolescents lasted between 12 to 30 minutes, with the average duration being 21 minutes. Children can “switch off” during the interview if they lose interest and find it difficult to concentrate. This is especially so for younger children. Furthermore, all children and adolescents who participated in this research were hospitalised, meaning that they were not entirely healthy, and could possibly become tired and disinterested after some time. I kept this in mind when speaking with the gatekeepers (both nurses and parents) as I recruited participants, always ensuring that the child was not in pain or distress which might limit their participation in the study. I was also observant of signs of “switching

off” while interviewing children so that I could pre-empt this and conclude the interview if needed. Such a situation arose on one occasion when a young girl aged 12 years, Bella was being interviewed. I noted during the interview that she appeared to be tiring and no longer showed interest in responding to my questions. I asked her if she was tired and when she answered “Yes”, I suggested we end the interview which she agreed with. After ending the interview and switching off the audio recorder I walked back to her room with her, where her Dad was waiting for her.

4.2.9.5 Using probing questions

According to Price (2002) interviews conducted with minimum probing often result in superficial accounts of the participants' experiences. He recommends the use of laddered questions to probe an issue. Laddered questions are arranged in order starting with a broad question and proceeding to deeper and more probing questions once the interviewer is sure the interviewee is ready (Price, 2002).

The first layer of questions were descriptive and used early in the interview to set the scene, put the participant at ease and let him/her know that I was interested in what they had to say. I paid close attention to non-verbal cues, such as body language or facial expressions that might indicate the participant was becoming uneasy. By paying attention to body language I believed I would recognise if the participant was becoming distressed and if it was appropriate or not to probe an issue further. “What has being in hospital been like for you?” was an opening question for the child and adolescent participants. In the case of a parent, I asked them to tell me what it has been like to be in hospital with their child. The aim of these broad opening questions was to encourage the participants to share their experiences, to tell their story in their own words. These opening questions also helped to put the participants at ease, since they were simply seeking a description of the participants own personal experience of being in hospital. Charmaz (2014; p. 66) refers to these first layer questions as “initial open-ended questions”.

Deeper and more probing questions were introduced only when the participant showed signs of being at ease and settled into the interview, when he/she was talking freely and sharing experiences readily. “What kind of things do you think the nurses should do for you while you are in hospital?” is an example of a level two question, which Price (2002) describes as a knowledge question while Charmaz (2014; p. 67) calls them “intermediate questions”. Such questions challenged the participants to think about the reasons for their answers, they also helped me, as researcher, to follow leads that may arise. It was important at this stage that I remained observant of any distress the participant may be experiencing as a result of my line of questioning. The participants' comfort is always the priority, even more important than obtaining what Charmaz (2014; p.66) calls “juicy data”.

If I felt the participant was becoming distressed, I had planned to return to more comfortable questioning to avoid further distress to the participant. This situation did not arise.

Towards the end of the interviews I used what Charmaz (2014; p. 67) refers to as “ending questions”, which aim to bring the conversation back to a more normal level, and convey a sense of completion to the interview. An example of an ending question I used is “After being in hospital, what advice would you give to someone who has just been admitted for the first time?” This question was added following preliminary data analysis of early interviews and review of the interview guide.

4.2.9.6 Managing silences

According to Corbin and Strauss (2015; p. 39) “One of the most difficult aspects of interviewing for beginning researchers is facing periods of silence.” These authors advise that the interviewee should guide the course of the interview, the interviewer should allow the participants to proceed at their own pace, giving them time to think before responding.

Allowing silences to play out until the participant was ready to speak again was a challenge for me in the beginning. While listening to the recording of the first interviews I reflected on the silences and made a conscious effort to refrain from filling these silences in future interviews. It was tempting to fill these silences, however Corbin and Strauss (2015) advise that these periods of silence are accepted and analysed for possible meaning. I was aware that rich information may be revealed as the participant relaxed and the relationship between them and I developed. By allowing the silences to come to their natural end, I believe I was allowing the participants to think and I was not putting them under pressure to respond quickly.

4.2.9.7 Keeping the participant focused

During the interview process, some participants shifted their focus from nursing care in hospital to other issues, sometimes topics related to challenges which made being in hospital even more difficult, for example financial difficulties. I always attempted to be aware of my reactions and how they might influence participants’ responses and the course of the conversation, in an effort to avoid influencing participants’ responses. Researchers need to “scratch below the surface” during the data gathering process in order to seek meaning in the data (Mills *et al*, 2006). I searched for more in-depth and more meaningful data by using open-ended probing and reflective questions which encouraged story-telling, and were included in the interview guide.

Corbin and Strauss (2015) advise that the researcher may bring the participant back to the topic being studied if he/she digresses and shifts the narrative to an unrelated topic. On one occasion a mother digressed off topic to talk about the challenges she faced while in

hospital with her daughter for a prolonged time. I listened attentively and respectfully to her, but took the first opportunity to politely refocus the discussion, using the interview guide to redirect the conversation to talking about her experience of her role in her daughter's care in hospital.

4.2.9.8 Ending the interview

At the end of each interview, when I was no longer recording, I chatted informally to the participants, acknowledging their contribution to the research and future healthcare practice. This informal chat with participants is important to ensure they do not feel they have been used. In some instances some valuable nuggets of information were discussed during this time. “End-of-interview revelations” are described by Corbin and Strauss (2015; p. 40) as new and often valuable insights that are discussed after the recorder is turned off. For this reason I always had a pen and notebook at the interview to take note of such “revelations”. I always asked for permission from the participant to take note of and use this new information in the research. When such “revelations” arose they were included as a footnote at the end of the transcript, which was returned to the participant by email to confirm accuracy of the content. This practice helped to add validity to the process, as participants were asked if they agreed with the content of the transcript, including any footnotes, and if it was an accurate reflection of what had been discussed at the interview. On one occasion Kate, the mother of a 15 year old girl, commented after the interview had ended and the recorder was turned off that the showering facilities for parents were “non-existent”. She had been in hospital for three days and had not had a shower since she left home. She was keen to ensure that a lack of such facilities was recorded but that she was not complaining. She was commenting so that things might improve for future parents when staying with their child in hospital.

4.2.9.9 Developing my interview skills

According to Charmaz (2014) the researcher reflects on, revises and develops the interview questions and his/her skills as the interviewing process proceeds.

In order to evaluate my interview style and develop my skills, I engaged in critical reflection following each round of interviews. This process involved reviewing the transcripts, critically listening to the recordings of each interview and discussing my interview style with my supervisors, who are both experienced qualitative researchers. My supervisors gave me constructive feedback, which helped me to develop and improve my interview skills, both in terms of asking probing questions and actively listening. I revised my approach to interviewing accordingly. Following the first round of interviews, I noted that I was filling the silences especially for the younger and more reticent participants. My supervisors pointed this out to me and advised me to allow the silences to come to their natural ending, and to

analyse them in the data. Throughout the data gathering stage of the study, I critically reflected on my interview style, which supported the development of my interview skills and my ability to sensitively collect quality data.

4.2.10 Data analysis

In grounded theory data analysis involves the researcher interacting closely with the data. The researcher asks analytic questions of the data, which enhances their understanding of the phenomenon (Corbin and Strauss, 2015). In constructivist grounded theory, data analysis comprises of three phases of coding which are referred to as initial, focused and theoretical coding (Charmaz, 2014). It is a slow, complex, time-consuming and sometimes frustrating task that involves systematically searching the raw data. It is a process that continues throughout the life of the project, rather than it being a defined stage of the process.

Data analysis in this study was a slow and labour-intensive process which, involved listening carefully to audio recordings of the interviews, transcribing them verbatim, reading the transcripts a number of times, coding the transcripts line-by-line, comparing codes with codes, identifying categories, selecting participants' quotations to reflect the codes and categories, identifying key concerns of the participants, allowing codes and categories to emerge from the data and ultimately, generating an explanatory theory grounded in the participants' data.

4.2.10.1 Transcribing the interviews

All interviews were digitally recorded using a hand-held audio-recorder and transcribed verbatim. While transcribing interview data in this way is time-consuming, there are some associated benefits. It allowed me to become immersed in the data, supported my development of a deep understanding of the participants' experiences, and promoted the generation of ideas that might otherwise be missed (Charmaz, 2014). All transcripts were compared with the voice recordings to ensure all data were captured accurately in the transcript. In order to avoid misrepresenting the participants' views, I sought validation by returning each transcript to the participant by email for confirmation that it represented what was actually said during the interview, as recommended by Charmaz (2014). Keeping a written record of what the researcher observes during the interview adds context and meaning to the interview data (Charmaz, 2014). Including any valuable additions to the conversation after the recorder has been turned off will also add to the richness of the data (Corbin and Strauss, 2015). Immediately after each interview, I completed field notes to capture in writing any observations I made during the interview, for example the setting, any non-verbal cues noted and any other reflections on the interview, which I considered of value to my understanding of the issues explored. These field notes were subsequently

used to provide background information to the interview data during data analysis. I also maintained memos where I recorded my reflections on how the interviews had progressed and if I had any concerns that I believed needed my attention, in terms of improving my interview skills, as reflected in the memo – *Reflections following Round One of data gathering* (Appendix 19).

4.2.10.2 Using NVivo software

Conducting qualitative data analysis manually with large datasets is not practical, especially in light of the computerised packages that are available to assist with such analysis. Over the last 20 years or more computer assisted qualitative data analysis software (CAQDAS) programmes to assist with qualitative data analysis have become increasingly available (Leech and Onwuegbuzie, 2011). Using a CAQDAS programme can make qualitative data analysis easier when compared to manual analysis (Bazeley, 2009), and enhance the quality of the study, especially when there is a large data set (Leech and Onwuegbuzie, 2011; Dalkin *et al*, 2021). Such programmes help in recording, storing, organising, sorting, and coding qualitative data (Bergin, 2011). A particularly useful feature is their ability to assist with data management when comparing categories and codes by linking data with data, (Bazeley, 2009; Foley and Timonen, 2014), in a consistent manner (Bergin, 2011).

I used NVivo2020 as a repository for the storage, organisation and management of transcripts and analytic memos. NVivo is a CAQDAS programme which has been designed and developed to manage coding and categorising procedures common in qualitative research (Hilal and Alabri, 2013). I attended a two-day workshop facilitated by QDAtraining in September 2020. Following this workshop there was support in the form of an expert user to guide me as I navigated the functions of NVivo. By using NVivo many of the administrative tasks associated with manual coding and retrieving of data were made easier, faster and more consistent. NVivo software allowed me to retrieve and review the data rapidly and comprehensively, to search for words and phrases, to label segments of data and to extract quotes, replacing the uncertain and slow process of manual searching and filing. I was always conscious of retaining the flexibility, creativity, insight and intuition needed to ensure maximum output from analysis, remembering that the software was not a replacement for systematic and inductive analysis. The data analysis must always be undertaken by the researcher.

Interviews were the main sources of data, the verbatim transcripts were saved as individual documents in NVivo. It was I, as the researcher, who was the main tool for data analysis as advised by Denzin and Lincoln (2018). I interrogated the data, and decided what to code and categorise. Through a process of analytical and creative thinking, together with my professional knowledge, the categories and main concerns of the participants emerged. NVivo allowed me more time to think about and analyse the data, discover similarities and

differences in the codes, and make conclusions. In addition, NVivo allowed me to attach memos, field notes and external files to any document, information that I believed to be important and add context, but that interrupted the flow of the transcript. These linked documents can be coded directly within NVivo, and were subsequently included in the data for analysis, helping to create an audit trail of decisions made about the data and the findings. They also helped to explain how analytic decisions were arrived at in relation to the data analysis process, adding to the transparency of the research (Dalkin *et al*, 2021). Writing memos and storing them within NVivo had many benefits over a paper copy, including being able to code the reflections and thoughts in the memos directly within NVivo.

In this study NVivo was found to be most useful during initial and focused coding. It was also helpful to collate and retrieve excerpts from transcripts. However, when analysing the data for more abstract categories, I found manual coding to be more productive. During the advanced data analysis stages, I found I needed to move between interview transcripts, memos, initial codes and focused codes as I constantly compared codes with codes, codes with categories, and categories with categories in the process of identifying the key concerns of the participants and the core categories. At this stage NVivo was used as a repository for transcripts, memos, initial codes and focused codes, while I worked manually to identify theoretical codes and categories and the participants' key concerns, which formed the emergent theory.

4.2.10.3 Initial Coding

Coding is an analytical process used to identify concepts in the data (Chun Tie *et al*, 2019). It is the process of analytically selecting, labelling and sorting the raw data (Charmaz, 2014). Charmaz (2014) refers to initial coding as deconstructing the data, by breaking it down into meaningful pieces, allowing the researcher to interact closely and analytically with the data and study each fragment of data. I coded in three phases – initial coding, focused coding and theoretical coding - in line with constructivist grounded theory (Charmaz, 2014), and in the process constantly compared the data for similarities and differences, as is a key tenet of grounded theory. I then grouped together initial codes that were conceptually similar into categories during focused coding and finally developed theoretical codes which contributed to the emerging theory.

I began initial coding by reading and re-reading each interview transcript in detail line-by-line, searching for incidents and actions to code. I coded anything that showed potential relevance using the participants' language to label the codes, known as *in vivo* coding, in an effort to force me to be open to as many possibilities as I could identify in the data. I kept these initial codes short and simple, and at the same time analytical, as recommended by Charmaz (2014), using active words to label them. Glaser (1978) described this as fracturing the data. Line-by-line coding in this way takes time and requires attention to

detail, it is important not to take shortcuts as it promotes conceptualising the data. This process, while laborious, gave me confidence that I was omitting nothing. I created initial codes freely, coding everything I considered was relevant to the participants' experience of being in hospital. I constantly compared data with data, initial codes with initial codes, within and between interviews, in an effort to identify patterns in the data and new ideas to pursue in future interviews. Seeing patterns implies seeing something repeatedly in one interview, or across a number of interviews (Sandelowski, 2001). Constantly comparing codes with codes in this way heightened my awareness of the direction the data analysis was taking, which guided the questions and probes to be asked during future interviews. It also informed further data collection through theoretical sampling.

As far as possible, I used active words when naming initial codes. According to Glaser (1992) using active words encourages the researcher to think about processes rather than descriptions. Some examples of initial codes are “Parents not doing the medical stuff”, “Not involving parents in planning care”, “Leaving it to chance”, “Being bored” and “Being lonely”. By using the participants' own words to name the initial codes I stayed close to the raw data. During the process of initial coding it was important that I was creative and patient, in order to identify meaningful codes, so that the codes assigned to the raw data reflected what the participants were saying. Two research supervisors reviewed this process repeatedly, and advised on the initial codes I was assigning to the data, which added trustworthiness to the process. Initial coding gave me a preliminary set of ideas, from where I began to explore and examine the data further, by asking new analytical questions of the raw data. It also gave me an improved understanding of the participants' world, and contributed to the development of categories during focused coding.

I coded the children's and adolescents' data as one dataset, and the parents' data as a second dataset. I feared omitting something important, and so coded line-by-line, using gerunds i.e. action words ending in “ing” and the participants' own words. I sought the advice of my supervisors regularly while I was analysing the data. See Appendix 20 for an example of a memo which reflects my concerns at this time. Appendix 21 provides a list of the most frequently occurring initial codes identified for children and adolescents. Appendix 22 is a presentation of the codebook of initial codes that I created from the parents' data.

4.2.10.4 Constant comparison analysis

Constant comparison analysis is at the core of grounded theory and was used throughout this study to analyse and compare new data with existing data, to develop codes, concepts and categories. Constant comparison analysis is achieved through working back and forth through the data, while simultaneously collecting, coding and analysing data, until a comprehensive set of categories is reached and new theory is generated (Charmaz, 2014), this means that initial coding is tentative.

Constant comparison analysis commenced following the first interview and continued throughout the data collection phase until the participants' key concerns were identified. I continuously compared data with data, incidents within the same interview and in different interviews. As I created codes I compared them with each other to form categories, and continued comparing codes with categories and categories with categories as I was collecting and analysing data, until I eventually arrived at a core category. Through the use of constant comparison analysis I began to recognise what was significant to the participants as I gained deeper insights into what it was like for them to be in hospital, and to what extent they wanted to be involved in their own care. I grouped data with similar characteristics together into codes. Two or more codes that shared similar features were grouped together to form a category.

While I analysed the data myself, I met with my research supervisors monthly while I was collecting and analysing data to critically discuss and assess how I was arriving at codes and categories. This process allowed us to gain a shared understanding of the raw data, it also challenged any assumptions I may have had that influenced the analysis, thus minimising the risk of personal bias, as described by Burnard *et al* (2008). I took on board the advice of McGhee *et al* (2007) who contend that staying true to the constant comparison method will minimise any preconceived bias as a result of pre-existing knowledge.

Through the process of constant comparison analysis, categories began to progressively develop from the initial and focused codes until the core categories emerged, as Bryman (2016) advised. I returned frequently to the raw data to determine if I needed to collect more data to support the codes and categories I was identifying. As I was collecting and coding new data, I continuously compared the new codes with existing ones. I sometimes needed to rename initial codes, which is consistent with Charmaz (2014) when she advises that initial codes are provisional and require a degree of fluidity, as data collection and analysis continues, and core categories are identified, which eventually lead to the new theory.

4.2.10.5 Focused coding

Focused coding involves sorting initial codes, synthesising and organising them into new categories that subsume numerous initial codes, it involves “coding your initial codes” (Charmaz, 2014; p. 138), condensing and sharpening them in an analytical way. Focused codes describe how two, or more, initial codes relate to each other, highlighting what the researcher finds to be important in the emerging analysis (Charmaz, 2014). Those initial codes which make the most analytic sense are examined for similarities and categorised, or clustered together into preliminary categories according to obvious fit (Stern, 1980; Charmaz, 2014).

As I continued to collect new data I examined the initial codes, searching for the most significant and frequently occurring ones, continuing to use constant comparison analysis. I revisited my initial codes, and compared initial codes with initial codes to see how they were similar to and different from one another. I searched for the most frequent or significant initial codes, and selected those that I believed made the most analytic sense and had most theoretical significance. I began to build on the initial codes by grouping similar codes together. The initial *in vivo* codes were collapsed into higher level categories at increasing levels of abstraction to create tentative focused codes. I continued to engage regularly with my supervisors during this process to ensure there was agreement with the focused codes that were emerging. The data broken down, or deconstructed, during initial coding were being transformed and reconstructed as focused categories emerged. Through constant comparison I was able to discover what was consistent and what varied among data, both of which are valuable contributions towards identifying a core category (a main focus of the emerging theory) and defining its properties. As the research progressed and categories emerged from the integration of codes, I returned to the data to confirm that the newly developed categories remained relevant and constant. This practice also helped to ensure that the data were not being forced into categories and that the categories represented what the participants said. In this way I checked if the preliminary findings were congruent with the new data being collected.

During focused coding, I asked two key questions of the data: “What are the participants’ main concerns?” and “What are the participants doing to help to overcome their concerns?” This helped to condense the number of initial codes into focused codes. Codes that were irrelevant to the main concern were placed to one side and considered false leads. As further data were collected, new emerging categories were identified; I then reconsidered previously analysed texts in light of the developing categories. I frequently returned to the codes that I had earlier placed to one side to check that they were truly irrelevant, and if any new data were similar to them that could form patterns and become significant data. I wrote many memos during this phase, expressing my thoughts and feelings of this stage of the analysis, see Appendix 23 for an example. Data analysis became more focused as categories were developed and saturated, as I attempted to identify the main concern of the participants and move closer to the formation of tentative core categories. An example of a coding strategy is presented in Appendix 24.

4.2.10.6 Memo writing

In constructivist grounded theory, memos are informal analytic notes written to self throughout the research process (Charmaz, 2014). They are a record of the researcher's thoughts, the comparisons he/she made between pieces of data, the questions he/she asked of the data and the leads he/she pursued. Simply put memos are a record of the

conversation the researcher is having with himself/herself about the data, emerging codes, ideas and hunches, allowing his/her views and assumptions to become known (Charmaz, 2014). Together, memos and coding provide a record of how the researcher has engaged analytically with the data in order to develop categories, providing direction for theoretical sampling (Corbin and Strauss, 2015).

While collecting data I was observant of the participants' non-verbal cues, how their voice was depicted in terms of tone and pitch, as well as their body language, as they described their experiences. I was keen to retain these non-verbal cues as I believed they could contribute to analytic ideas. Charmaz (2014) advises that writing a memo about such ideas as they occur can preserve them so that the researcher can return to them at a later stage during data analysis. In line with Saldaña's (2013) advice to use only the most relevant memos in the final report, I have included the most salient memos to provide justification of the data analysis process. Memo writing was an important component in the data analysis process, as it helped me to think analytically about the data and the emerging codes and categories. I wrote them as brief notes to myself on my reflections of the data collection and data analysis processes, usually recording challenges I was facing. Reviewing memos made me think about possible leads in the data that needed to be followed and helped me identify possible sources of further data. They also made me aware of any personal assumptions and added to the quality of my data analysis. I progressed from writing memos in a descriptive fashion, to thinking more analytically about emerging codes and categories. Memos also provided an audit trail of my thoughts behind the decisions I made, helping to demonstrate accountability and trustworthiness of the study.

4.2.10.7 Theoretical sampling

According to Charmaz (2014; p. 197) "initial sampling in grounded theory gets you started; theoretical sampling guides where you go." Theoretical sampling promotes the strategic recruitment of participants who may have varying experiences of the phenomenon being studied, and who can add rich insights to the emerging concepts or categories following initial data analysis, in order to learn more about those concepts. It is less concerned about the demographic characteristics of the participants, such as age, gender or social class, and more concerned about the contribution future participants can make to the emerging theory. Charmaz (2014) cautions against using theoretical sampling too soon, advising to begin theoretical sampling only when relevant ideas or concepts have been identified and need more probing in order to develop them further.

Once the first round of data gathering was complete and the interviews were transcribed I began preliminary analysis of the data and creating initial codes. I worked hard to identify recurring patterns and the emerging key concerns of the participants. For example, I recognised that I needed to explore further the concept that it seemed important to the

children, and especially to the adolescents, that they were supported to do what they could for themselves while in hospital. This concept emerged in the context of the child/adolescent doing their own personal or intimate care for themselves. I also recognised that younger children were not sharing their experiences with me as freely as older children and adolescents. For this reason I decided that I needed to recruit more adolescents for future interviews. Adolescent participants were more engaging and articulate, and I believed that I would gain richer insights from them. Thus purposive sampling was replaced with theoretical sampling, which allowed me to be more specific in selecting who to interview next, to seek out participants who could contribute to the tentative categories and key concerns that had emerged to date from initial coding. As a result, data gathering became more focused, aiming to gather data to constantly compare with earlier data and give further insights into the emerging categories as data collection, analysis and the process of developing an explanatory theory continued. My initial codes did not fully explain the participants' experiences, I recognised gaps in the codes and needed to clarify and develop these codes and categories further. This preliminary data analysis process informed the revision of the interview guides following each round of data gathering and directed me to the next participants. Through theoretical sampling I continued to collect more focused data, following leads I had identified during data analysis, clarifying uncertainties, checking hunches and constantly comparing codes and categories as the research progressed. This data contributed to the development of focused categories, and the emergent key concerns and core categories of the participants, and eventually to the explanatory theory. I continued this process as the theory developed until saturation was reached and the core categories were identified.

4.2.10.8 Theoretical coding

Stern (1980; p. 22) describes theoretical coding as comparing categories with categories to identify how they connect, advising the researcher to ask "Is there some higher order category, some umbrella under which all these categories fit?" According to Charmaz (2014) theoretical codes build on focused codes by framing the emerging theory. They account for all other codes and categories that have been identified in earlier coding and analysis.

I began theoretical coding by reflecting deeply, and for a prolonged period, on the codes and categories developed during initial and focused coding, as I moved towards discovering the core categories. I identified the participants' main concerns, and condensed the recurring patterns into action words, that explained in a few words what the research was about. Finding the right words was difficult, it took time and many takes, before I was satisfied that I had picked the correct words and placed them in the correct order. I wanted to be sure the final core category pulled all the key concerns of the participants together.

Strauss and Corbin (1998; p. 146) describe this process as one that “consists of all the products of analysis condensed into a few words that seem to explain what ‘this research is all about’”. I engaged frequently with my research supervisors throughout this process, by zoom or email. They were instrumental in advising, supporting and eventually agreeing with me on the final theoretical codes chosen. When our interpretations of the data differed, we discussed them frankly and at length, until we reached a consensus and agreed on the most appropriate words and codes to represent the participants' experiences and the meaning of the data.

During initial and focused coding, data became fragmented. During theoretical coding I began to weave the data back together again, relating earlier codes and categories to each other. I continued to compare categories with categories, searching for theoretical links between them. In this advanced phase of data analysis I wanted to raise the analysis to a higher analytical level, I was searching for the final emergent grounded theory. As a novice grounded theory researcher, I found this phase of data analysis particularly challenging. Memo-writing and the advice of my supervisors were invaluable in reconstructing the fractured data back together into the explanatory theory. Appendix 25 is an example of a memo I wrote during this time. The theoretical codes emerged from the focused codes. In line with Charmaz's (2014) advice I avoided applying theoretical codes that used professional jargon to the final explanatory theory. I wanted the final theory to be easily understood for the participants who were not from the nursing or healthcare world. My wish is that the explanatory theory emerging from this study will be understood by all those who participated in this study, including the adolescents and children.

4.2.10.9 Data saturation

In the process of theoretical sampling the researcher returns to the field again and again to collect more focused data that will add to the researcher's understanding of the phenomenon being studied. Saturation of categories is reached through the use of theoretical sampling (Corbin and Strauss, 2008) which continues as the theory is developing and until saturation is reached (Charmaz, 2014). Data saturation is reached when no new insights relevant to existing categories and sub-categories are identified from the new raw data being collected, when similarities and variations in emerging categories can be explained by the data already gathered and analysed (Charmaz, 2014).

Data saturation was considered to have been reached in this study following analysis of 23 child/adolescent interviews and 24 parent interviews. At this stage the raw data being gathered were no longer generating any new insights relevant to existing codes or categories. During this study I processed the entire dataset myself, I conducted all the interviews, I transcribed them all verbatim, I coded and categorised the raw data myself, and in doing so I got to know the data intimately, and did what Morse (2015; p. 588) refers

to as researchers “getting inside their data”. When discussing my research with my supervisors after Round Three of data gathering, I noticed I had stopped talking about individual participants and began talking about them in a generalised way, for example “Children want their parents to provide emotional support for them while in hospital” and “Parents see themselves as a comforter for their child in hospital”. Speaking in this way about my research reflected a degree of confidence on my part that I had likely reached saturation. Nonetheless, I continued to gather further data to confirm my thoughts and reassure myself that there were indeed no new concepts emerging from new raw data. Round Four of data gathering included 16 interviews in total (two children; six adolescents and eight parents). Following analysis of the data gathered in Round Four, I was able to say with confidence that data saturation had been reached. Similarities and differences in the codes that emerged from this round of data could be explained by earlier data. I was beginning to express the emerging theory in my conversations with my supervisors. In total I interviewed 47 participants. I believe that as a novice researcher I required more participants than a more experienced researcher might need in order to see the data clearly, and to develop the explanatory theory from them. Sandelowski (1995) describes this lack of experience as a contributing factor to a larger number of participants for novice researchers, as their research skills develop with experience. I consider myself to be a novice researcher, with my research skills still developing. The more I am learning and the further I travel along this research journey, I realise how much more there is to learn.

4.2.11 Reflexivity and the role of the researcher

Reflexivity is an awareness on the part of the researcher of the impact his/her personal and professional knowledge and social background has on the research process and the research outcome (McGhee *et al*, 2007). It is a continuous process of self-reflection on how the researcher's own values, beliefs and experiences influence data analysis and interpretation of the findings (Parahoo, 2014).

From the beginning I approached this study from a reflexive stance. Before gathering data I reflected deeply on my philosophical position. It was important that my philosophical position was congruent with my chosen methodology. I explicitly articulated my personal and professional knowledge and the experiences that motivated me to explore children's and parents' experiences and expectations of being in hospital. By conducting a concept analysis and a literature review at the early stages of this study, I was being open and honest about any prior knowledge that I brought to the study. When gathering and analysing data, I worked hard to remain open to all possibilities within the participants' descriptions of their experiences. In addition, I maintained a reflexive journal and contemporaneous field notes to record any thoughts and ideas that I believed would enhance the findings. I also wrote many memos, documenting my assumptions and thoughts about the data and what they

might reveal, reflecting an awareness of self which is integral to reflexivity. I remained in regular contact with my research supervisors, either by email or through planned supervision meetings, to support the progress of the study and my interpretations of the participants' data. My reflexive approach is evident throughout this thesis, I have been explicit about my reflections as my research journey progressed, documenting them at each stage of the journey. In the final chapter of this thesis, I will present a personal reflexive account which will outline the experiences and learnings I gleaned as a result of conducting this study.

4.2.12 Chapter summary

This chapter was presented in two parts. Part one began by outlining my personal worldview and what motivated me to explore this topic. Common research philosophies were described briefly, and my personal philosophy in detail. Frequently used qualitative methodologies were presented. The evolution of grounded theory from its origins to constructivist grounded theory was explained, and the rationale for choosing constructivist grounded theory was given. A framework for conducting a constructivist grounded theory study was described. Part two of this chapter presented the techniques I used to conduct this study, including the ethical principles, gaining consent, and the strategies use to sample, collect and to analyse data. How I used these techniques and the literature supporting my use of them was also presented. The chapter concluded with the role of reflexivity in the research process.

This study used semi-structured interviews to gather data from children aged nine to 12 years, teenagers aged 13 to 16 years and parents of hospitalised children. In chapter five I will present the study findings in detail.

Chapter 5

The Findings

“She [my Mum] just supports me like ... when I'm sick she can play with me and take my mind off things.” (Izzy; 10 year old female).

5.1 Introduction

This study aimed to explore children, adolescents' and parents' experiences and expectations of their roles in hospital. Key objectives were to identify children's and adolescents' experiences and expectations of their parents' involvement in their care in hospital, and their preferences for involvement in their own care in hospital. Other objectives were to explore parents' experiences and expectations of their role in their child's care in hospital and their perspectives of their child's role in their own care in hospital.

This chapter begins with a description of the demographic details of the study participants. The data gathering phase is then contextualised within the Coronavirus Disease 2019 (COVID-19) pandemic. The emergent grounded theory is presented in a diagram. The findings are presented using the major categories as headings. The categories were grounded in participants' data. The findings from the children and adolescents are presented, followed by those from the parents.

5.2 The context of the study

5.2.1 The hospital setting

This study was conducted in a large tertiary referral children's hospital in Dublin. The research sites were four general ward areas: ward A was a 22-bedded ward for children with orthopaedic and gastroenterology conditions; ward B was a 22-bedded general medical ward; ward C was a 15-bedded surgical ward specialising in ear, nose and throat conditions and burns/plastic surgery, and ward D was a general surgical ward with 10 beds. All clinical areas accommodated children and adolescents between two and up to the eve of their 16th birthday.

5.2.2 Overview of the study participants

The sample included hospitalised children aged nine-12 years old (n=9), adolescents aged 13-15 years old (n=14) and parents of hospitalised children (n=24). Five of the children were female and four were male, while ten adolescents were female and four were male. Of the parents interviewed, 20 were mothers and four were fathers. The participants' demographics are provided in Tables 5.1, 5.2 and 5.3 below.

Table 5.1 Demographic data of child participants

Child number	Gender	Age	Number of siblings	Acute or chronic condition	Ethic origin	Nights in hospital
Round 1 using Interview Guide Version 1 (January 2020)						
1 (Alan*)	Male	9yrs & 11mths	2	Acute surgical (foot injury)	Irish	2 nights - shared room
2 (Bella)	Female	12yrs & 3mths	1	Chronic medical (gastroenterology)	Irish child – Parents Romanian	3 nights - shared room (wheelchair user)
3 (Colin)	Male	10yrs & 3mths	1	Acute medical (gastroenterology)	Irish	5 nights - single room
4 (Dora)	Female	9yrs & 10mths	1	Chronic medical (T1 diabetes mellitus)	Irish child – Mother South African	2 nights - single room
Round 2 using Interview Guide Version 2 (March 2020)						
5 (Ethan)	Male	12yrs & 8mths	3	Chronic medical (T1 diabetes mellitus)	Irish	3 nights - shared room
Round 3 using Interview Guide Version 3 (November 2020)						
6 (Fiona)	Female	11yrs & 11mths	3	Chronic medical (Rheumatology)	Irish	7 nights - single room
7 (Grace)	Female	12yrs & 5mths	2	Chronic medical (T1 diabetes mellitus)	Irish	6 nights - shared room
Round 4 using Interview Guide Version 4 (June/July 2021)						
8 (Harry)	Male	11yrs & 4mths	0	Acute orthopaedic condition	Irish	10 nights - single room
9 (Izzy)	Female	10yrs & 9mths	0	Chronic condition (musculoskeletal)	Hungarian	4 nights - single room

* Pseudonyms were used throughout to protect the participants' identity.

Table 5.2 Demographic data of adolescent participants

Adolescent number	Gender	Age	Number of siblings	Acute or chronic condition	Ethnic origin	Nights hospital in
Round 1 using Interview Guide Version 1 (January 2020)						
1 (Amy*)	Female	15yrs & 4mths	2	Acute medical (Respiratory)	Irish	4 nights - single room
Round 2 using Interview Guide Version 2 (March 2020)						
2 (Brian)	Male	13yrs & 6mths	2	Acute surgical (Abdominal pain)	Irish	7 nights - shared room
3 (Gemma)	Female	14yrs & 10mths	2	Acute surgical (Elective orthopaedic)	Irish	3 nights - single room.
4 (Henry)	Male	14yrs & 1 mth	0	Chronic medical (Neurology)	Irish	9 nights - single room
Round 3 using Interview Guide Version 3 (October-November 2020)						
5 (Colleen)	Female	15yrs & 7mths	0	Chronic medical (Gastroenterology)	Irish	6 weeks - single room
6 (Diana)	Female	13yrs	1	Acute surgical (Appendectomy)	Irish	5 nights - single room
7 (Elena)	Female	15yrs & 7mths	2	Acute surgical (Abdominal pain)	Irish	2 nights -a single room
8 (Frank)	Male	13yrs & 3mths	2	Chronic medical (Neurology and cardiology)	Irish	4 nights - shared room
Round 4 using Interview Guide Version 4 (July 2021)						
9 (Inez)	Female	15yrs & 9mths	1	Chronic condition (Gastroenterology)	Irish	7 nights - single room
10 (Jane)	Female	15yrs & 11mths	1	Chronic condition (gastroenterology)	Irish	5 nights - single room
11 (Kelly)	Female	13yrs	2	Chronic condition (T1 Diabetes, first admission)	Irish	4 nights - single room
12 (Lottie)	Female	13yrs & 3mths	2	Acute trauma (Complex fracture)	Irish	1 night - shared room (2 nights previously).
13 (Molly)	Female	15yrs & 4mths	1	Chronic condition (Gastroenterology)	Irish	16 weeks - single room
14 (Nick)	Male	14yrs & 7mths	2	Recurring acute illness (Recent admissions x4)	Irish	7 nights - single room

* Pseudonyms were used throughout to protect the participants' identity.

Table 5.3 Demographic data of parent participants

Parent number	Mother / Father	Age range	Educational level attained	Number of children at home	Ethic origin	Condition of child – acute or chronic	Nights in hospital
Round 1 using Interview Guide Version 1 (December 2019-January 2020)							
1 (Anne*)	Mother	40-50 yrs	3 rd level	3	Irish	Sports injury	3 nights in shared room
2 (Berna)	Mother	Did not reply	Did not reply	3	Irish	Bone injury	2 nights in shared room
3 (Cathy)	Mother	40-50 yrs	2 nd level	3	Irish	Acute medical condition	4 nights in single room
4 (Dana)	Mother	50-60 yrs	3 rd level	3	Irish	Chronic medical condition	6 nights in single room
5 (Eithne)	Mother	30-40 yrs	Did not reply	2	Irish	Acute medical condition	5 nights in single room
6 (Freda)	Mother	40-50- yrs	3 rd level	3	South African	Chronic medical condition	2 nights in single room
Round 2 using Interview Guide Version 2 (March 2020)							
7 (Gerry)	Father	40-50 yrs	3 rd level	3	Irish	Acute surgical condition	7 nights in single room
8 (Hanna)	Mother	40-50 yrs	2 nd level	4	Irish	Chronic medical condition	3 nights in shared room
13 (Mary)	Mother	50-60 yrs	2 nd level	1	Irish	Chronic medical condition	9 nights in single room
Round 3 using Interview Guide Version 3 (October-November 2020)							
9 (Irene)	Mother	40-50 yrs	2 nd level	1	Irish	Chronic medical condition	6 weeks in single room
10 (Jackie)	Mother	40-50 yrs	Did not reply	2	Irish	Acute surgical condition	5 nights in single room
11 (Kate)	Mother	50-60 yrs	2 nd level	1	Irish	Acute surgical condition	2 nights in shared room
12 (Laura)	Mother	40-50 yrs	2 nd level	3	Irish	Chronic medical condition	4 nights in shared room
14 (Niall)	Father	40-50 yrs	3 rd level	4	Irish	Chronic medical condition	7 nights in single room
15 (Orla)	Mother	40-50 yrs	3 rd level	3	Irish	Chronic medical condition	6 nights in single room
16 (Paula)	Mother	50-60 yrs	2 nd level	2	Irish	Chronic medical condition	4 nights in single room

Table 5.3 continued Demographic data of parent participants

Parent number	Mother / Father	Age range	Educational level attained	Number of children at home	Ethnic origin	Condition of child – acute or chronic	Nights in hospital
Round 4 using Interview Guide Version 4 (June-July 2021)							
17 (Rita)	Mother	50-60 yrs	3 rd level	1	Irish	Acute orthopaedic condition	10 nights in single room
18 (Sarah)	Mother	50-60 yrs	2 nd level	2	Irish	Chronic medical condition	7 nights in single room
19 (Tara)	Mother	40-50 yrs	2 nd level	2	Irish	Chronic medical condition	5 nights in a shared room
20 (Ursula)	Mother	40-50 yrs	2 nd level	1	Hungarian	Chronic medical condition	4 nights in single room
21 (Valarie)	Mother	40-50 yrs	2 nd level	3	Irish	Chronic medical condition (first admission)	4 nights in single room
22 (Owen)	Father	50-60 yrs	3 rd level	3	Irish	orthopaedic injury	2 nights in shared room
23 (Wayne)	Father	50-60 yrs	3 rd level	2	Irish	Chronic medical condition	16 weeks in single room
24 (Yvette)	Mother	50-60 yrs	2 nd level	3	Irish	Recurring acute illness	7 nights in single room

* Pseudonyms were used throughout to protect the participants' identity.

In total 47 individual face-to-face interviews were conducted. Every effort was made to recruit a diverse group of participants in terms of age, gender and ethnicity. Participants represented a wide range of ages including children from aged nine to 12 years and adolescents from aged 13 to almost 16 years. Nine children and 14 adolescents took part in the study. Fourteen (61%) of this combined group were admitted for the management of a chronic condition, two of these were newly diagnosed and in hospital for the first time. The remaining nine (39%) were in hospital for the first time for the management of an acute illness.

However, despite actively seeking to include participants from ethnically diverse backgrounds, it can be seen from the Tables above that only one child was not of Irish origin and only two parents were not of Irish origin, all adolescents were ethnically Irish. Two additional children were from families who originated outside Ireland. As described earlier, purposeful sampling was used to begin this study, followed by theoretical sampling, in an effort to obtain participants who could provide rich insights into the phenomenon being studied. This sampling strategy is a key tenet in constructivist grounded theory (Charmaz, 2014). It was not possible to include a more culturally diverse population in this study for a

number of reasons. During data collection there were not many children and parents in the clinical sites where data were gathered, who were not ethnically Irish. All potential participants on the wards who were not ethnically Irish and whom the gatekeepers deemed suitable to be asked to participate, were approached. In most cases they declined, citing various reasons such as that they spoke English poorly, that their child was nauseated or in pain, or that they needed to leave the hospital on an errand and did not want their child to take part without them being present. Furthermore, I had hoped to include members of the Irish Travelling community as participants, but I encountered none in hospital during the data collection phase.

Only four fathers participated. Very few fathers were identified in the wards where data gathering took place. When a father was present with his child, I always discussed with the gatekeeper the appropriateness of seeking their participation. Only one father whom I approached declined to participate because he and his child were expecting a healthcare professional to visit and they wanted to be available, as they had been waiting for this consult for some time. While there is widespread support for gender equality worldwide (Pew Research Center, 2020), mothers remain the dominant parent when caring for sick children in hospital in Ireland. Other studies have also reflected this predominance of mothers as research participants when their child is in hospital (Coyne and Cowley, 2007; Hughes, 2007; Shields *et al*, 2008; Uhl *et al*, 2013; Romaniuk *et al*, 2014; Rostami *et al*, 2015; Abdelkader *et al*, 2016; Seliner *et al*, 2016; Curtis and Northcott, 2017; Foster and Whitehead, 2017; Okunola *et al*, 2017; Arabiat *et al*, 2018; Children in Hospital Ireland, 2020).

5.2.3 The context of data gathering in the COVID-19 pandemic

The findings of this study must be framed in the context of an international pandemic. The impact of the COVID-19 pandemic generated feelings of uncertainty, fear, anxiety and personal loss for many people throughout the world (Davidson *et al*, 2020; Lessa *et al*, 2022). The measures that were taken to limit the spread of the virus, including reduced movement as a result of national lockdowns and the resultant loss of face-to-face communication with loved ones, had a disruptive effect on everyone.

Data gathering began on the 13th December 2019. After transcribing the first parent interview (the mother of a male adolescent with a sports injury), I emailed a copy of the transcription to the participant asking her to review it, and to let me know if she was satisfied with its content, if she believed it reflected the conversation we had in the hospital. I sent this email on 16th of December 2019. As I was sending the email I realised I was asking this mother of three (one who was only just out of hospital) to read and confirm the content of a transcript immediately before Christmas, probably the busiest time of the year for any parent, especially one who had spent three nights (four days) in hospital with her son. My

email request was only going to add more work to this family's preparation for Christmas, which had already been interrupted by their son's injury and hospitalisation. For this reason I decided to defer any further interviews until after Christmas 2019. I began interviewing again on 9th January 2020 and completed Round One of data gathering on 23rd January 2020. There were 11 interviews in total in Round One (four children, one adolescent and six parents). These interviews were conducted during “normal” times in the hospital when no restrictions were in place.

During national lockdowns researchers were not allowed access to the hospital, however once the lockdowns were lifted we were given access again, although some restrictions remained in place. All remaining interviews (n = 36) were conducted within the context of the pandemic. Data gathering for Round Two was completed during early March 2020, while Ireland was in the containment phase of the COVID-19 pandemic, before the first national lockdown. I did not gain access to the hospital again until October 2020 to collect data for Round Three which was completed in November 2020. There was another national lockdown in January 2021 which lasted until the end of April 2021. I completed data collection in July 2021. During Rounds Two, Three and Four of data gathering there were significant restrictions on families attending the hospital as a result of the pandemic.

5.2.3.1 The COVID-19 restrictions

When I began Round Two of data gathering, the first confirmed case of COVID-19 in the Republic of Ireland had already been announced, on 29th February 2020. At this point, Ireland entered the containment phase in an effort to prevent community transmission. Containment strategies included social distancing, frequent hand washing, good respiratory etiquette and reduced social contacts. Despite such measures, the number of people testing positive for COVID-19 in the community rose significantly during early March. On 11th March 2020 the World Health Organisation (WHO) declared COVID-19 to be a pandemic. On 12th March 2020 the Government of Ireland declared a national lockdown to commence with effect the following day. This involved the closure of schools and all non-essential services such as hospitality and live entertainment, while people in non-essential services worked from home. During this phase the number of patients in hospital in Ireland with COVID-19 escalated exponentially, while hospital staff were also infected, leaving the health services overwhelmed. Data gathering during Round Two ceased prematurely due to the restrictions, which denied any unnecessary personnel, including researchers, access to the hospital. There were seven interviews in total in Round Two (one child, three adolescents and three parents). Round Three of data gathering was conducted in October/November 2020 and included 13 interviews (two children, four adolescents and seven parents). Round Four was completed in June/July 2021, and included 16 interviews (two children, six adolescents and eight parents).

While the first national lockdown was not enforced until after the premature ending of data gathering in Round Two, Ireland was already in the containment phase. Restrictions were in place in hospitals since February 2020 to mitigate against the spread of the virus. These restrictions included such measures as only allowing one parent in the hospital with the child, not allowing any extended family or friends to visit and the closure of all school classrooms, play rooms and parent rest rooms in the clinical areas to prevent congregation and the associated risk of increased spread of the virus. Furthermore, hospitalised children and their parents were not allowed to leave the clinical area to visit cafés, shops or other social outlets in the hospital. Communal family areas, such as parent rest rooms, were closed. These restrictions remained in place in the hospital setting for the duration of data gathering.

5.2.3.2 The impact of COVID-19 restrictions on families in hospital

There is currently very limited evidence on the effects of such restrictions on hospitalised children and their families. Bannerman *et al* (2021) explored the experiences of parents when their child was in the Paediatric Intensive Care Unit (PICU) in a children's hospital in Scotland. These researchers found that while parents of children in this PICU understood the rationale for the restrictions during the pandemic, they felt isolated and distressed, and missed the support of their partner while their child was in hospital. Parents reported experiencing reduced opportunities to interact with their child and their partner, as well as with the healthcare staff. These missed opportunities all contributed to the parents feeling overwhelmed as a result of their limited ability to support one another while their child was in hospital (Bannerman *et al*, 2021). Al-Motlaq *et al* (2021) urged healthcare professionals to deliver the necessary elements of family-centred care (FCC), in order to support families and to achieve FCC during the COVID-19 pandemic. They called for more awareness among healthcare professionals of the importance of child- and family-centred care and the potential adverse impact on hospitalised children and their families of failing to implement such an approach to care during the COVID-19 pandemic (Al-Motlaq *et al*, 2021). As a result of only one parent being allowed to stay with their hospitalised child, the risk of that parent becoming emotionally and physically fatigued was greater in the context of them not being relieved by the other parent to go home for even one night to have a proper night's sleep. The hospitalised child and the parent who was staying with them were separated from the other family members, which is not congruent with FCC and may have led to further distress. Additionally, the child in hospital during the COVID-19 pandemic was confined to a small space with one parent, which can give rise to an intense and challenging situation.

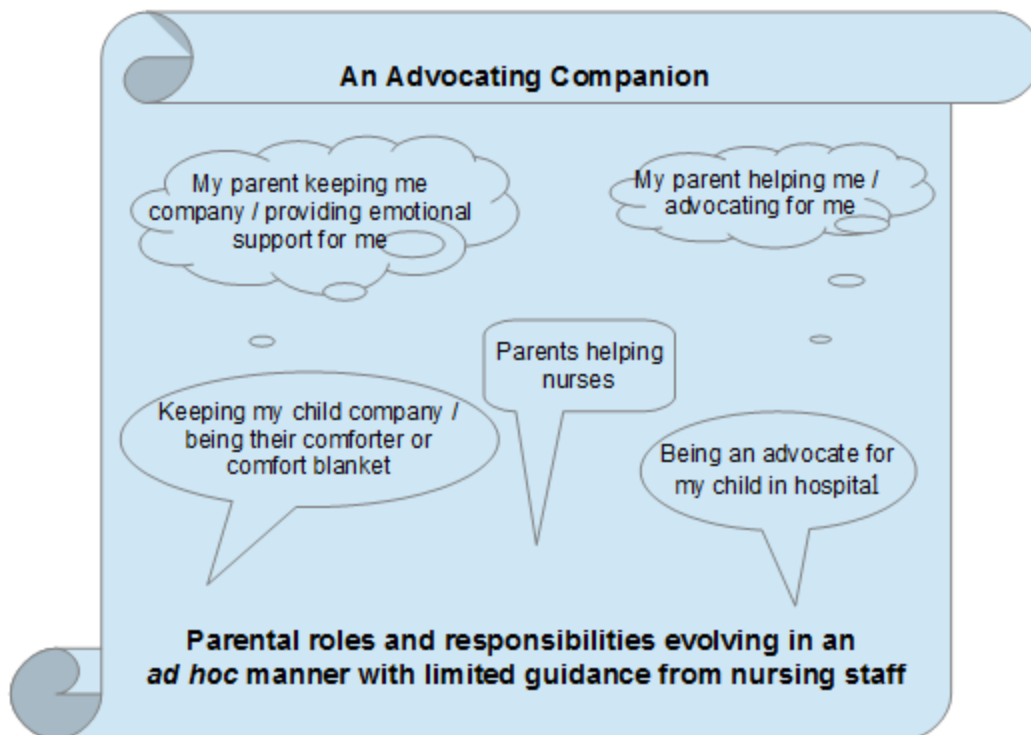
5.3 The emergent grounded theory

Consistent with constructivist grounded theory, the aim is to produce a theory that explains participants' main concerns (Glaser, 1992; Charmaz, 2006; 2014). Saldaña (2013) describes a theory as a single sentence with associated words which expand its meaning, advising the researcher to capture the totality of the analysis in one sentence.

5.3.1 The core category common to all participants

There were three categories common to all participants: 1) “parents helping and advocating for their hospitalised child”, 2) “parents providing emotional support, comfort and companionship for them” and 3) “parental roles and responsibilities evolving in an *ad hoc* manner over time with limited guidance from nurses”. Thus, the theory emerging from this study to explain parents' roles and responsibilities while they are in hospital with their sick child during the COVID-19 pandemic is: “*An advocating companion with parental roles evolving in an ad hoc manner during the COVID-19 pandemic with limited guidance from nursing staff*”. See Figure 5.1 below for a graphical representation of how the grounded theory was reached, and the major categories which were subsumed to form it.

Figure 5.1 A grounded theory of “*An advocating companion with parental roles evolving in an ad hoc manner during the COVID-19 pandemic with limited guidance from nursing staff.*”



According to Charmaz (2014) theories shed light on what is unknown about a phenomenon. Although several aspects of the theory of FCC have been discussed in this thesis, in both the concept analysis (Chapter Two) and in the literature review (Chapter

Three), the end product of this study was the development of a theory that makes explicit the child's role and the parents' role in hospital during a pandemic. The theory "*An advocating companion with parental roles evolving in an ad hoc manner during the COVID-19 pandemic, with limited guidance from nurses*" adds to the body of nursing knowledge by identifying how children, adolescents and their parents perceive the role of the parent while in hospital with a sick child, while restrictions were imposed as a result of a global pandemic.

In the following sections the findings are presented using the major categories as headings, illustrating how the theory was developed. The categories are grounded in participants' data, the words they used to describe their experiences and expectations while in hospital were used to label the categories. The findings from the children and adolescents are presented, followed by those from the parents.

5.4 The findings from interviews with hospitalised children/adolescents

Sick children and adolescents admitted to hospital come from a range of different cultural and social backgrounds. They bring with them a variety of different life and healthcare experiences. Their expectations of healthcare will be informed by their previous, if any, experiences. For some children and adolescents in this study being in hospital was their first encounter with the healthcare services, meaning they could not rely on personal previous experience. The expectations of these children are likely to be informed by the experiences and expectations of their parents, family or friends. The key concerns of the children and adolescents in this study are discussed below using their words as headings to describe the emergent categories:

- a) My parent keeping me company / providing emotional support for me
- b) My parent helping me / advocating for me
- c) Taking care of myself / doing my own personal care.

5.4.1 My parent keeping me company / providing emotional support for me

The children and adolescents included in this study were aged between nine and 16 years. The concept of their parent being present to keep them company was a common feature in many interviews, with children and adolescents frequently commenting how important it was to them to have their Mum or Dad with them in hospital as a source of company and emotional support.

"She [my Mum] could stay while I was having my cannula inserted, she just sat there to be with me ..." (Colin; 10 year old male).

“They [my parents] are here to em ... like to distract me ... like to make me happier instead of being in here by myself.” (Grace; 14 year old female)

The children and adolescents were explicit about their parent being a source of emotional support while they were in hospital, and referred to this frequently.

“I was crying, a complete emotional mess. You know it is just really good, it would be so awful if I didn't have my Mum here” (Diana; 13 year old female).

“No, I wouldn't have been able to do it [be in hospital] without my Mum staying, I'd have been much more anxious.” (Elena; 15 year old female).

The lack of personal face-to-face contact with their wider family and friends while in hospital during a pandemic may have heightened the children's and adolescents' need to have their parent present for company. Furthermore, the child's dependence on their parent for company and social interaction may have been more pronounced as a result of the restrictions in place due to the COVID-19 pandemic, which was a similar feature with their parents. There was also the absence of activities which normally happen in the hospital environment to keep children occupied during the day, such as school and play activities.

“She [my Mum] just supports me like em ... when I'm sick she can play with me and take my mind off things.” (Izzy; 10 year old female).

“It's so nice to have someone to talk to, and that makes me feel less lonely.” (Inez; 15 year old female).

It is well documented in the literature that being in hospital is a frightening experience for children and adolescents (Moorey, 2010; Ford, 2011; Coyne and Kirwan, 2012). This frightening environment may have contributed to the fact that many children and adolescents in this study described being in hospital without a parent as being difficult to imagine.

“If they [my parents] weren't here after my surgery, then it'd be just so hard to cope with everything.” (Gemma; 14 year old female)

“It's just nice to have your Mum here and it's just like, you know, really reassuring.” (Diana; 13 year old female).

Appendix 26 Table One provides a graphical presentation of how the major category for children and adolescents – My parent keeping me company / providing emotional support for me - was reached. The key initial codes which contributed to the constituent

subcategories / focused codes are also included. When analysing data and developing categories, Charmaz (2014) recommends comparing initial and focused codes to construct more abstract categories, these abstract categories will then be subsumed by higher level categories to form major and core categories. Illustrating connections and comparisons between initial codes and emerging categories through the use of tables and diagrams in grounded theory demonstrates how theoretical coding was achieved and is an integral part of the process of advanced data analysis in grounded theory. It helps to provide a visual representation of the core elements of the resultant grounded theory (Charmaz, 2014).

5.4.2 My parent helping me / advocating for me

Parents helping their children and advocating for them while in hospital represents the way in which children viewed their parents' role while they were in hospital. There was a strong sense of the parent being present to help their child/adolescent to do what they were not able to do for themselves.

“My Mum has been looking after me and helping me with stuff that I can't do myself ..., you know physically, I can let her do it” (Harry; 11 year old male).

There was evidence that some of the children and adolescents expected their parent to help them with personal care when they were unable to do it themselves.

“I had to use the bedpan [’cos I was unable to walk] and my Mum helped me with it.” (Harry; 11 year old male)

“When I was really sick my Mum helped me go to the bathroom, and have a shower and personal care like that.” (Nick; 14 year old male).

While the children and adolescents did not explicitly mention their parent acting as an advocate for them, they described their parent performing advocating activities, such as speaking to the nurses and doctors on their behalf. They appeared to understand the importance of this aspect of their parents' presence and role with them in hospital.

“My Mum makes sure like that I am getting seen, ’cos I wouldn't just go up to a doctor and be like “Hey...” Like say if I'm in pain she'll help me get the nurse.” (Jane; 15 year old female).

“Like if I felt sick or something she'd [my Mum] help, my Mum would like tell me to breathe or something, and then she might go ask the nurse could I have some paracetamol or something ...”.(Kelly; 13 year old female).

In the context of the parent helping the child in hospital there was frequent reference to the

parent's role in tasks that were generally described as "medical", which represented a constituent sub-category: "*Parents doing the medical stuff*". Those children who were in hospital for the first time for treatment of an acute illness were clear that they did not want their parent to do what they called the "medical stuff". They expressed being afraid that their parent might not be sure about what to do and might do something wrong.

"I definitely think my Mum could do something wrong, because she has never done anything like that [wound care, checking my pulse and blood pressure] before so, ..." (Jane; 15 year old female first admission for a newly diagnosed chronic condition).

"I don't think we [my parents and I] should have to do [adjust] the brace because that helps with re-adjustment and re-alignment of my broken leg. I'd feel more comfortable if the doctors and nurses did that since they know what they're doing, and they know how and where to move it to." (Lottie; 13 year old female).

Many of the children and adolescents in this study believed that the nurses' job was to do the "medical stuff" as they were trained to do it, and hence they believed that was their responsibility. These children and adolescents were mostly in hospital for the first time and predominantly had an acute illness.

"I like that the nurses are doing that [checking temperature, blood pressure and oxygen saturation] 'cos I know they know exactly what they're doing." (Amy; 15 year old female).

"Well that's [the "medical stuff"] the nurses' job and they know how to do it properly." (Kelly; 13 year old female).

Many believed that their parent was not the right person to do cares that they considered "medical" such as wound care, adjusting infusions and monitoring their temperature.

"I think the nurses should be the ones doing the medical things like changing drips and cleaning wounds, because parents can only do so much and the nurses have been trained for this, parents haven't." (Jane; 15 year old female).

However, children and adolescents with a chronic condition were generally more confident with their parent doing care activities that they described as the "medical stuff", which seemed to be related to the confidence gained from them doing such care activities during repeated hospitalisations and at home. All of these children and their parents were linked to a chronic care service within the hospital and were receiving the support of a Clinical Nurse Specialist (CNS).

“She [my Mum] helps me with my BiPAP and the cough assist which helps me cough, she holds my head in position, she moves my legs sometimes.” (Izzy; 10 year old female with complex care needs)

“I have to flush my nasojejunal tube very, very slowly, otherwise it gives me very bad pain. So I prefer my parents doing that because they [my parents] know exactly how I like doing that, 'cos it's different for every person. So my parents are used to using the nasojejunal tube at home.” (Molly; 15 year old female with a chronic condition).

The coding framework for this category - parents helping me/advocating for me – is presented in Appendix 26 Table Two. The key initial codes which contributed to focused codes are also included.

5.4.3 Taking care of myself / Doing my own personal care

The children and adolescents in this study described looking after themselves and doing their own personal care as important to them. For many of them it was important that they were able to do their own intimate care.

“I’m not really allowed go to the bathroom which is a bit annoying 'cos I can’t walk, so they [the nurses] have to bring in a commode, oh it’s the worst thing ever!” (Amy; 15 year old female).

The idea of a nurse having to help the child with intimate care appeared almost offensive to some of the adolescents in this study. It is not uncommon for this age group to express such feelings, as they become more aware of their changing body image. They are also asserting themselves as they seek to become independent of their parents and develop the skills of self-care.

“I don’t like people seeing my scars or my central line, 'cos my body is badly scarred and stuff, and I wouldn’t show anyone my stomach or anything.” (Colleen; 15 year old female).

Even the younger children in this study described a desire to be able to do their own intimate care themselves, instead of the nurse or their parent doing that for them.

“The nurse just puts me in the bath and I manage on my own then, yeah. ... I’d prefer to go to the toilet and do my bath on my own.” (Bella; 12 year old female with a physical disability).

“I’d prefer my Mam or Dad to watch me do my lancet at night, ... the injection into my leg. It’s not ideal having to take your pants down when you’re in front of someone you don’t really know.” (Ethan;

12 year old male).

The importance of doing their own personal care and not being dependent on the nursing staff or their parents was a common feature for many children and adolescents of all age groups in this study.

“I kept taking my medication and I got better and better as the days went on, now I'm able to go to the toilet by myself.” (Harry; 11 year old male).

Many children and adolescents described doing what they could for themselves as being important. Their desire to regain health, independence and eventually go home was referred to frequently.

“I'm trying to do the most I can do, you know to get back to normal life so that I can go home soon.” (Harry; 11 year old male).

“They [the nurses and doctors] said I can come off my drip if I start drinking more fluids, so I drank more fluids and I came off the drip.” (Jane; 15 year old female).

Many children and adolescents mentioned that keeping themselves busy was an important self-care role while in hospital. This concern is likely to have been heightened by the absence of other activities in the hospital because of the pandemic restrictions.

“I'm watching stuff on Netflix, which is nice ... 'cos due to COVID no visitors can come in, so you just get used to like entertaining yourself.” (Lottie; 13 year old female).

“I do a lot of like art work to keep myself busy. It could become just one long night time, rather than like getting up and starting your day and then doing stuff during the day, trying to keep a routine going.” (Molly; 15 year old female).

Children were comforted and supported by the familiar and constant caring presence of their parent in an unfamiliar and often frightening environment.

“I think it's much better to have your parents here 'cos like they can help you.” (Kelly; 13 year old female).

A presentation of how the category for children and adolescents – Taking care of myself / doing my own personal care - was reached is available in Appendix 26 Table Three. The initial codes which contributed to the focused codes are included.

5.5 Findings from interviews with parents of hospitalised children

A core category that emerged from the parents' data was that of the parents keeping their child company in hospital and being a source of companionship for them. This finding is set in the context of a global pandemic and the associated restrictions imposed on families in the hospital to suppress the spread of COVID-19. Other major categories that emerged from the parents' data are also presented below in narrative form and illustrated in table format in Appendix 26. Tables are used to demonstrate the initial codes which contributed to the creation of focused codes, which then were subsumed into the major categories for parents. The five key concerns of the parents are discussed below using their words as headings to describe the emergent categories:

- a) Keeping my child company / Being their comforter or comfort blanket
- b) Advocating for my child
- c) Limited negotiation with nurses about the role of the parent
- d) Parents helping the nurses
- e) Parents “making do with” inadequate facilities.

5.5.1 Keeping my child company - being their comforter or comfort blanket

Keeping them company represents a major concern of parents in this study. Parents often referred to their key role as that of being a source of comfort and support for their child within the context of ensuring that their child was not alone in hospital, which appeared to be important to them. As one parent explained:

“I'm a kind of support network for her ... I'm her “dodie”, she knows she's not on her own up here.” (Sarah; mother of a 15 year old female).

This comment was made in the context of the adolescent being in hospital for the first time and a long distance from home. Sarah believed her child was feeling very vulnerable. A “dodie” is another name for a pacifier, which is used to soothe a baby or small child in distress. The word “pacifier” is more associated with the American culture. In our culture we frequently use the terms “soother”, “dodie” or “dummy” to describe a pacifier which is used by a very young child as a source of soothing comfort and satisfaction. Older children in Ireland generally do not use a “dodie”, instead they often use what we refer to as a “comforter”, or a “comfort blanket”, which they cling to for comfort and support when they are frightened or distressed in unfamiliar, uncomfortable or threatening surroundings. This is often a favourite blanket or soft toy, which the child uses to soothe him/her when distressed. By comparing initial and focused codes, abstract categories were arrived at

until the parent being a source of comfort and support for their hospitalised child became a major category.

There were many examples of parents who viewed themselves as their child's "comforter", a source of comfort and support for their hospitalised child, for example,

"They [children in hospital] are out of their comfort zone, they need their parent as that little crutch to support them while they're here [in hospital]." (Niall; father of 11 year old female).

"If there's any degree of, ... you know a little bit of worry, a little bit of anxiety, a little bit of discomfort, a little bit of ... go get a nurse or go get a doctor, that's my role, it's to support her and to make sure that she has somebody familiar around on who she can rely." (Owen; father of 13 year old female).

Some parents mentioned that there was not a lot for children to do in hospital and that the day was very long for both their child and themselves. The sense that the parent was a source of company for the child in hospital was evident from many parents' conversations.

"There's just not a lot going on for them [children in hospital]. They're sitting in bed all day long, they're just watching the television." (Hanna; mother of 12 year old male).

"She doesn't have to sit here on her own, being sad and anxious." (Tara; mother of 15 year old female).

The coding process that contributed to this major category is illustrated in Appendix 26 Table Four.

These references to parents being a source of comfort for their child in hospital and their child needing company appears to have been heightened by the restrictions imposed on society, and on children and families in hospital, due to the COVID-19 pandemic. Hospital playrooms, classrooms and cafés were not available to the children as a source of play, learning and socialisation while the data for this study were collected. Only one parent was allowed to stay, in an effort to minimise the number of people circulating in the hospital and reduce the risk of COVID-19 spreading. Furthermore, visitors and volunteers who might often provide distraction for the child and a break for the parent, were not allowed in the hospital. As parents were not allowed to alternate to relieve one another, the role of "keeping them company" was intensified and rested solely on the parent who was staying with the hospitalised child. There were no restrictions in place during Round One of data collection. It is possible to say with some degree of certainty that this phenomenon appeared to be less important for the six parents who were interviewed in Round One, when

there were no restrictions in place. When reviewing the initial codes which were subsumed to form this category, very few of them emerged from the data of the six parents in the first round of interviews. It did appear that keeping their child company in hospital was more of a concern for parents in Rounds Two, Three and Four of data collection when strict restrictions were in place. However, it is worth noting that the interview guide became more focused as data gathering progressed which may have influenced this finding.

5.5.2 Advocating for my child

Within the context of providing company for their hospitalised child, of being a source of comfort and emotional support for them, many parents referred to their role in hospital as that of representing their child or acting as an advocate for their child.

“My role is to be a champion for my child.” (Paula; mother of 16 year old female).

“I had to be his voice, when he was too sick to talk to the nurses.”
(Yvette; mother of 14 year old male).

Frequently the parent believed the child was unable or unwilling to speak on their own behalf and it was important that they were present to do so for their child.

“She [my daughter] can ask me things and I can ask the nurses and the doctors for her, 'cos she might not feel comfortable doing that.”
(Valarie; mother of 13 year old female).

The role of parents as their child's advocate was often described in the context of the challenges and frustrations associated with it, in terms of maintaining relationships with the nurses and not stepping on their toes.

“I suppose I'm copped on enough to know when to say nothing, when to sit back. The last thing you want to do is get in their [the nurses] way.” (Rita; mother of 11 year old male).

Advocating as strongly as possible for their child was an important role for the parents, but involved some careful negotiations and discussions in an attempt to avoid upsetting the nurses. It appeared important to some parents, especially those of children with a chronic condition who attended the hospital regularly, that a good relationship between the nurse and the parent, and by default the child, was maintained at all costs. Wayne's daughter had a chronic condition and attended hospital frequently, on this occasion they were in hospital for an extended period.

“So you get stuck in that parent mode that you're trying your best to act as her advocate. ... It's like trying to walk a tight rope. ... As parents, we have to advocate as strongly as possible. I think

sometimes we struggle with that. But that's the politics of it."

(Wayne; father of 15 year old female).

On one occasion frustration was expressed by a parent at the possibility of missing out on a specialist medical team review if she had not raised the issue with the nurse before her daughter's planned discharge home.

"So, if I hadn't raised it with them and the nurse hadn't said "OK yeah no problem, I'll chase that up", we might have left here without ever seeing the dermatology team." (Paula; mother of 16 year old female).

It is clear that the parents in this study were keen to act as strong advocates for their hospitalised child. However, it appears they spent time and energy trying to maintain a good relationship with the nurses, trying to avoid stepping on their toes while advocating as best they could for their child. The metaphor "walking a tight rope" was used by one parent to describe this balancing act. The initial and focused codes that contributed to this major category are illustrated in Table 5 in Appendix 26.

5.5.3 Limited negotiation with nurses about the role of the parent

Parents who accompanied their sick child to hospital and participated in this study came from a variety of backgrounds and brought with them different life and healthcare experiences. Their expectations of their roles in hospital with their child was likely formed by their previous experiences of being in hospital, for many parents (n=9 - 31%) it was their first time in hospital with their child. Nonetheless, most parents spoke about limited formal discussion or negotiation with the nurses to plan the care activities they were to carry out and to explain what was expected of them. Consequently, their roles and responsibilities evolved in an *ad hoc* manner over time with limited formal planning or agreement with the nursing staff.

"We never really sat down and discussed it [helping my daughter with the bedpan] in black and white, but it was implied that I was happy to do it, and they [the nurses] were happy to let me do it." (Dolores; mother of 17 year old female).

"There was no discussion, there was no guidance to the parents, it just happened ... it happened naturally." (Niall; father of 11 year old female)

Some parents claimed that they "just knew" what to do, as if it was common sense. They described learning what was appropriate to do for their child by finding out for themselves and from watching other parents.

“I suppose we kind of fall into what we see other parents doing, and what our place is, without having to discuss it with the nurse. It’s unsaid ...” (Rita; mother of 11 year old male).

“Sometimes you’re kind of having to go and find out for yourself.”
(Paula; mother of 16 year old female).

Many parents assumed that what they were doing was appropriate, as there was only minimal guidance from the nursing staff. They described waiting for someone to tell them if they were doing things wrong.

“No one told me to stop, so I must be doing something right!”
(Dolores; mother of 17 year old female).

While parents spoke about the importance of them being involved in the care of their child in hospital, many of them also talked about their lack of knowledge and experience of “the medical stuff” saying that they would prefer the nurses to do those tasks that required more “medical” knowledge. This idea appears to be as a result of parental fear of doing something wrong or missing an important indicator that their child's condition may be deteriorating.

“The temperature and stuff, I’d be happy to let someone else do that for him, because they (the nurses) are tracking that, and I would be afraid I’d do something that wasn’t right” (Anne; mother of 13 year old male).

“I prefer not to do the medical things that I wouldn’t have a clue about.” (Jackie; mother of 13 year old female).

Some parents described a sense of fear and responsibility that if they did something they were not sure about, it could cause unnecessary pain, discomfort and even medical complications for their child. In the main this fear was described by parents of children who were acutely ill, and often on their first admission to hospital.

“After she had the scoliosis operation, the rods came away from the spine. I thought it was something that I had done. You know this is very complex and I’ve no medical background whatsoever, so I blamed myself.” (Dolores; mother of 17 year old female)

Dolores' daughter had a chronic medical condition but was in hospital on this occasion for a surgical procedure. This was a new, and apparently frightening, experience for Dolores and her daughter.

Generally parents of children with a chronic condition appeared to be more comfortable about being involved in the “medical stuff”. This may be because they have had experience of managing their child's chronic condition at home for a period of time and have had specialist education and training from the nurses, doctors and other healthcare professionals, such as dieticians or physiotherapists. In some cases these parents were performing “medical” procedures at home, such as injecting insulin, measuring blood and urine glucose levels, connecting and disconnecting total parenteral nutrition infusions and managing chronic pain. In all cases they had accompanied their child in hospital on more than one occasion. Mary, whose son had a chronic condition and had been in hospital many times, explained this phenomenon very well.

“The nurses just leave us to our own devices, because we know exactly what we’re doing.” (Mary; mother of 14 year old male).

In all cases where it was evident that the parent was more comfortable carrying out the “medical stuff” in hospital, the children and their parents were linked closely with a chronic care service within the hospital, which included the support of a CNS. They described being supported by the nursing staff when they are at home.

“She [the Clinical Nurse Specialist] is absolutely the top one on my list ... she's been fantastic. I can ring her or text her when we're at home, which is fantastic” (Irene; mother of 15 year old female).

In the absence of a formal discussion with the nurse about their role, parents in this study appeared to be unsure of their roles and responsibilities while in hospital with their child. Instead, their role appears to have evolved in an *ad hoc* manner, where they learned from observing other parents on the ward and proceeded to care for their child until they were told otherwise. The major category for parents: “Limited negotiation with nurses about the role of the parent” and its constituent subcategories is presented in Table 6 in Appendix 26.

5.5.4 Parents helping the nurses

Within the context of a lack of formal negotiation with nurses about their role, parents often described how busy nurses were, and that parental presence and parental involvement in care was not only a great help to the nurses but was also expected of the parents as explained by Paula.

“They [the nurses] were very much towards encouraging the parents, involving them, including them, and I suppose to some extent getting us to do as much as possible.” (Paula; mother of 16 year old female).

Other parents described how they believe their presence was a help to the nurses, some believing that it would not be possible for their child to be properly cared for in hospital without a parent present.

“I think they [the nurses] are actually happy that there's a parent here and involved, I think it helps their job a lot, makes it a lot easier for them.” (George, father of 13 year old male).

“I can't envisage it [my child's hospital care] happening without a parent present. ... It just wouldn't work without a parent being present, I genuinely couldn't see how.” (Owen, father of 13 year old female).

Another parent who works in the community as a healthcare assistant and whose child has complex care needs appeared to believe strongly that her presence in hospital with her daughter was a great help to the nurses.

“I think I'm a really helpful person for the nurses, because I am her carer at home so I know what I'm doing. I'm working as a healthcare assistant for other people, part-time when my husband is not working. Yeah, so I absolutely am a big help for the nurses.” (Ursula, mother of 10 year old female).

Ursula is the primary carer for her daughter who has complex care needs, requiring assisted ventilation, suctioning, nasogastric feeding and physiotherapy at home. Ursula manages all this complex care at home and was now staying in hospital with her daughter who was having an elective procedure. Ursula described staying in the room with her daughter at all times and being “relieved” by the nurse when she went to the cafeteria to eat or to the bathroom to shower.

“When I'm going just for a few minutes out [of the room], she [my daughter] needs a nurse to be here with her in case ... because she can't move herself at all. So yeah, a nurse will come and stay with her while I am out of the room, it's great, it works well for us.” (Ursula, mother of 10 year old female).

Ursula also described calling the nurse to help her when her daughter needed repositioning or toileting, explaining that she needed help with her daughter in hospital because she was in pain and had various infusion lines in place, otherwise she could have done all this without the help of the nurses.

“But it's very good that the nurses are here and you know they are very helpful” (Ursula, mother of 10 year old female).

In this situation the role of the nurse involved medication management, monitoring the child's condition and co-ordinating care. Other parents described how they helped the nurses, who were always busy.

“You’re conscious of the workload of the nurses all the time, so definitely we’re here to help them.” (Niall, father of 11 year old female)

“He’s been having a bath every day because of his eczema, but I’ll be there, I tell the girls [the nurses] to go off. I say “Do you want to go off and do something else, I’ll call you when I need you.” (Rita; mother of 11 year old male).

Table 7 in Appendix 26 illustrates how this major category was arrived at.

5.5.5 Parents “making do with” inadequate facilities.

Many parents in this study expressed their acceptance of less than optimal sleeping, showering and eating arrangements for themselves, making it clear that they were not complaining. Another major category was identified as that of parents “making do with” the sleeping, showering and eating arrangements available to parents in hospital.

“The [yoga-style] mats on the floor, they’re not very comfortable but they are great, you’re so delighted to get them on the first or second night. By the end of the week though, you do ... like my back is killing me now, my shoulders are killing me.” (Jackie; mother of 13 year old female).

All parents in this study stayed with their child in hospital for more than two nights. Although some parents described being in hospital with their child as difficult and exhausting, they were reluctant to complain or to blame the hospital or ward management for the inadequate facilities for parents who chose to stay with their child.

“I know the mattress [yoga mat] isn’t the most comfortable thing in the world, but I’m not here for comfort, I’m here for my child’s care. I slept on it for a week ... so no I’m not complaining.” (George; father of 13 year old male).

“I slept here for the last few nights, it’s a hospital you know, there are people here who are distressed, there’s noise, there’s lights and all that, ... I accept that, but it’s difficult.” (Rita; mother of 11 year old male).

Many parents commented that they were in pain as a result of the sleeping arrangements, but were just glad to be able to stay with their child.

“You're not at a great angle for sleeping, the sink is in the way, and then the base [of the chair] juts out and you're afraid you are going to impede the nurses and others trying to get in [to the room]”. (Kate; mother of 15 year old female).

“I mean it's [the parent's bed] not like at home, but at least I have a bed, it's very narrow, I'm just always sleeping on my side and I feel it in my back.” (Ursula; mother of 10 year old female).

Such sleeping arrangements mean that the parent is unlikely to have a comfortable night's sleep and raises the question - how reasonable is it to expect parents to function and to make important healthcare decisions with and/or on behalf of their child without a comfortable night's sleep? These healthcare decisions often require considerable questioning and deliberation in order to explore all possibilities, before coming to an informed conclusion. The lack of sleep and consequent tiredness as a result of sleeping on a “yoga mat” on the floor can only add to the parents' anxiety while their child is in hospital. One mother put it very well when she commented:

“It's a tough thing to go through, to stay calm and stay sane with very little to no sleep and obviously you're worried as well. I'm surprised there's not more, you know, more outbursts ... but yeah, it's not easy for parents at all here.” (Freda; mother of 9 year old female).

Less than optimum eating arrangements were also described by some parents, which only add to this issue.

“So I end up going to the cafe downstairs [to eat], the canteen is very limited in its opening hours. Having somewhere for a proper meal that's more accessible for greater hours would be a great help.” (Kate; mother of 15 year old female).

“If you're hungry or you're tired, it can push you over the edge.” (Paula; mother of 16 year old female).

By keeping their child company, providing emotional support for them while in hospital and by advocating for their child, parents felt they were contributing to their child's care, giving them a sense of purpose by being able to participate in their child's recovery and well-being. By helping the nurses, parents believed they were being supportive of the busy nursing

staff, while making do with less than optimal eating, showering and sleeping arrangements was necessary in order to be with their child in hospital.

“If I’m not sleeping in the night, ... I have to be here with my child. If I’m not sleeping I do not have energy so it’s quite difficult you know to find the balance.” (Ursula; mother of 10 year old female).

Table 8 in Appendix 26 illustrates the initial and focused codes that made up this major category.

5.6 Chapter summary

The categories presented in this chapter illustrate the nature of the children's and adolescents' involvement in their own care in hospital and the role of their parents. Many children/adolescents described their parents' key role while in hospital with them as that of helping them and advocating for them. Parents keeping their child company in hospital was another major concern for them. In terms of their involvement in their own care, they frequently described being unable to do what they wished to do for themselves while in hospital as difficult for them, especially in terms of performing their own personal intimate cares, like using the bathroom and showering. One female adolescent described not being allowed to go to the bathroom on her own as “the worst thing ever”.

Many of the parents described their role as a companion and comforter for their child in hospital. However it must be acknowledged that this may be as a result of the restrictions imposed due to the COVID-19 pandemic. Other key concerns of the parents were acting as an advocate for their hospitalised child, having limited negotiation with nurses about their roles and responsibilities, being a source of help for busy nurses and “making do with” inadequate facilities.

These findings will be discussed in the next chapter in the context of relevant existing literature. The explanatory theory explaining the involvement of the child and parent in care in hospital will be presented, which is grounded in the participants' data.

Chapter 6

Discussion

“Family-centred care needs to integrate concepts of child-centred care, .we respectfully suggest it be revised from family- and child-centred care to child and family centred care so that the child is positioned to come first rather than secondary to family” (Ford et al, 2018)

6.1 Introduction

In this chapter the key findings are discussed in the context of existing literature on family-centred care (FCC) of children and adolescents in hospital. As advised by Charmaz (2014) the major categories/key concerns of the participants will be used as headings. The emergent explanatory theory, which is grounded in the participants' data, is described. Charmaz (2014) asserts that constructivist grounded theory assumes the researcher's values, priorities and position and that the emergent theory is always contextual, and sometimes partial. How this study, its findings and the theory generated from it add to the existing body of knowledge and to our understanding of the topic will also be discussed.

This study used a constructivist grounded theory approach (Charmaz, 2006; 2014) to explore children's, adolescents' and parents' experiences and expectations of their roles in hospital. The objectives of the study were to:

1. Identify children's / adolescents' experiences and expectations of their parents' involvement in their care in hospital,
2. Explore children's / adolescents' experiences of engagement and role preferences in their own care in hospital,
3. Explore parents' experiences and expectations of their role in their child's / adolescent's care in hospital,
4. Explore parents' perspectives of their child's / adolescent's role in their own care in hospital,
5. Develop a theory to explain the involvement of the child / adolescent and parent in care in hospital.

For ease of reading, children and adolescents will simply be referred to as children from this point on. Most of the data for this study (36 of 47 interviews - 77%) were collected during the Coronavirus Disease 2019 (COVID-19) global pandemic, when there were significant restrictions imposed on parents and children in hospital in an effort to minimise the risk of COVID-19 entering the hospital. There is no doubt that being in hospital while such restrictions were in place was more challenging for both the children as patients and their parents, than being in hospital during "normal" times. However, it is now almost three years since the first case of COVID-19 was detected in Ireland. Some infection prevention and control restrictions remain in place in healthcare settings to minimise the risk to vulnerable patients of contacting the virus, although to a lesser extent. Hospital playrooms and school classrooms are operational, with reduced numbers allowed to attend. Hospital cafés are open as social spaces, but with smaller capacity. Only one parent is allowed to stay with their hospitalised child, and the other parent, siblings and friends are not allowed to visit. The parents are now allowed to relieve one another which was not the case during data collection for this study. Volunteers have not yet returned to their roles as a source of

distraction for the child and a relief for the parent, by keeping the child company while the parent takes a break from the bedside. Parents are still required to wear a face mask while in the hospital. It is not yet known when such restrictions will be completely lifted and extended family, friends and volunteers will be welcomed freely again to the healthcare setting in the way they were pre-pandemic. The findings of this research and the ensuing discussion must be viewed in this context. This study is the first of its kind to be conducted in an Irish children's hospital during a pandemic. Consequently, the findings are novel and reflective of the experiences and challenges children and parents experienced while in hospital during a pandemic.

The key concerns which formed the major categories of the hospitalised children who participated in this study were:

- a) Parents keeping me company and providing emotional support for me,
- b) Parent helping me and advocating for me
- c) Taking care of myself / doing my own personal care.

The key concerns forming the major categories of the parents who participated in this study were:

- a) Parents keeping their child company -being a source of comfort, emotional support and companionship for their hospitalised child,
- b) Parents being an advocate for their child in hospital,
- c) Limited negotiation from nurses about the role of the parent - parental roles and responsibilities evolving in an *ad hoc* manner over time,
- d) Parents helping the nurses,
- e) Parents "making do with" inadequate facilities.

Charmaz (2014) asserts that comparing the major categories with existing literature on the topic is the final stage of data analysis and will lead the researcher to the core concept and the emergent grounded theory. Progressive analysis of the data in this way will eventually reveal one thing that is common to all the participants, and this will become the explanatory grounded theory (Charmaz, 2014; Hoare *et al*, 2012). The core concept which forms the grounded theory subsumes lesser categories and is more significant (Charmaz, 2014). It accounts for more data and makes more explicit the most important actions of the participants'. In other words the resulting theory is co-constructed with the participants and is grounded in their data. Using the key concerns/major categories as headings to guide the discussion, further analysis of the findings in the context of the existing literature will be discussed, outlining how the theory to explain the hospitalised child's role and their parent's role while in hospital was reached. Charmaz (2014) advises that constructivist grounded theory assumes the researcher's values, priorities and position, and that the emergent theory is always contextual. The theory resulting from these comparisons is the researcher's

interpretation of the participants' data. The emergent theory emphasises interpretation and promotes improved understanding above explanation, recognising the subjectivity of both the participants and the researcher(s).

6.2 Parents providing companionship, comfort and emotional support for their child in hospital

Parents providing emotional support, comfort and companionship for their hospitalised child was a key concern of most participants. The children believed that their parents' key role in hospital was to be a source of emotional support and company for them. It was important to the children that they were not alone while in hospital. As a result of the restrictions imposed during the COVID-19 pandemic, only one parent was allowed to stay with their child, and visitors were not allowed during this time. Communal social spaces like playrooms and school classrooms were not available, while children and their parents were asked not to visit the cafés in the hospital in an effort to minimise the risk of spreading the virus. Such restrictions are likely to have contributed to the children feeling more isolated and possibly lonely while in hospital. They frequently mentioned that their parent was present as a source of emotional support and company for them, some commenting that being in hospital was boring and would be very difficult if their parent was not present. Likewise, the parents believed that their key role while in hospital with their sick child was to keep their child company. Parents often referred to themselves as being a source of comfort and emotional support for their child within the context of ensuring that their child was not alone in hospital, which appeared to be important to them. Their presence was to be a comforting companion for their child in hospital.

This is not a new finding, as parents providing emotional support for their child in hospital has been frequently reported in the literature on FCC over many years. In a critical literature review conducted as part of this research (see Chapter 3) many FCC studies concur with this finding, recognising that parents' presence provided emotional security, comfort and reassurance for the child in hospital (Coyne and Cowley, 2007; Hughes, 2007; Ames *et al*, 2011; Coyne, 2013; Higham and Davis, 2013; Romaniuk *et al*, 2014; de Macedo *et al*, 2017; Foster and Whitehead, 2017; Matziou *et al*, 2018; North *et al*, 2020; Ohene *et al*, 2020; Fisk *et al*, 2022). This phenomenon was described by Coyne (1995) when she found that mothers participated in basic childcare rather than any technical nursing procedures, and provided emotional support. Parents wanted to stay with their child because they were concerned “for their child's emotional and physical welfare” (Coyne, 1995; p. 76). It has also been acknowledged that being in hospital can be boring for children, and that the presence of a parent can be a source of relief (Coyne and Cowley, 2007), through chatting, reading and playing (Coyne, 2013), especially when the child is being cared for in a single room (Curtis and Northcott, 2017). Similarly, Clarke (2022) reported that hospitalised

children were lonely and bored because the nurses were too busy to chat to them, and there were only minimal play specialists available.

Coyne and Kirwan (2012) also concur with these findings, in a qualitative descriptive study exploring the wishes and feelings of being in hospital with 55 hospitalised children in Ireland. They found that some children were afraid while in hospital and talked about not feeling safe if they are alone. These findings were also supported by Coyne (2013) who reported that children wanted their parent to stay with them, because they felt more secure when their parent was present to provide comfort and reassurance for them. Romaniuk *et al* (2014) in a Canadian study found providing comfort and emotional support for their child was a key care activity for parents when their child was in hospital. A systematic review of qualitative studies (n=14) identified parental presence as a source of emotional support and security for the child in hospital (Watts *et al*, 2014). Bedells and Bevan (2016) in a review of primary research studies on nurses' and parents' perceived roles when a child is in hospital, recognised that parents stay with their children in hospital to provide basic care and emotional support.

Similarly, in an exploratory study of parents and staff perceptions of FCC in a children's high dependency unit (HDU) in New Zealand, family presence and parental involvement in the child's care was found to be central to meeting the child's psychosocial, emotional and physical needs (Foster and Whitehead, 2017). Boztepe and Kerimoğlu Yıldız (2017) reported similar findings in a qualitative study in Turkey, asserting that nurses believed children felt safer and more comfortable in hospital when their parents were with them. Likewise, Curtis and Northcott (2017) found that hospitalised children are vulnerable and rely on the care and support of their parents. In a review and meta-analysis of parents' coping support interventions while their child is acutely ill in hospital, Doupnik *et al* (2017) acknowledged that encouraging the parent to provide emotional support for the child in hospital was central to a FCC approach to children's healthcare delivery. More recently, in an integrative review of FCC practices for hospitalised children and their families in developing countries, Phiri *et al* (2020) reported that families are an important source of support and strength for children in hospital. Prasopkittikun *et al* (2020) in a mixed-methods study examining the differences between perceptions and practices of FCC among children's nurses in Thailand, also recognised that parents' role when their child is in hospital was to provide emotional support and comfort for them. Fisk *et al* (2022) explored the experience of parents of children in a Paediatric Cardiac Intensive Care Unit (PCICU) in a large urban children's hospital in the United States of America (USA), and found that parents described their role as that of being there to provide physical and emotional support for their child in hospital. In a qualitative descriptive study conducted in a tertiary children's hospital

in Australia, Taranto *et al* (2021) also found that “being with” their child following a surgical procedure in hospital was a key concern for all the parents in the study.

However, not all studies on FCC have recognised parental presence in the context of keeping the child company and being a source of emotional support as a core parental activity of parents when they are in hospital with their child. In a systematic review of qualitative studies on FCC (n=11) by Shields *et al* (2006), the researchers did not describe parents keeping their child company or providing emotional support for them while in hospital as core elements of FCC. Likewise, Coyne *et al* (2016) did not refer to parents providing emotional support for hospitalised children as a core principle of FCC in a discussion paper comparing a family-centred approach to a child-centred approach to care. Additionally, parents keeping their child company was not identified as a core element of FCC in an integrative review examining FCC from the perspective of parents of children in a paediatric intensive care unit (PICU) (Hill *et al*, 2018a). This may have been because the children were critically ill and possibly intubated, ventilated and sedated, and the parents may not have considered keeping their child company as a key role in that setting. Furthermore, in a concept analysis (O'Connor *et al*, 2019) the four key attributes of FCC were identified as being: parental participation in care, the development of respectful and trusting partnerships, information sharing and all family members as care recipients. Parents providing company and emotional support for their child in hospital were not recognised as attributes in the theoretical articles included in that analysis.

Since this study was set in the context of a global pandemic, providing company and emotional support for their hospitalised child was the responsibility of the sole parent who was staying in the hospital. It was clear from the children who participated that it was difficult for them to imagine what being in hospital without their parent would be like. Infection prevention and control restrictions on families attending, and on visiting in general, such as those imposed during the pandemic, are frequently imposed on a short-term basis during the winter months in Ireland when there is an infectious disease outbreak such as a high incidence of influenza, or other debilitating viruses, in the community. Consequently, allowing only one parent to stay with their hospitalised child, and restricting visits from siblings and grandparents, may become the new norm in an effort to minimise risks of emerging infections, especially during the winter months. Two adults alternating, either both parents, or a significant other adult known to the child who can relieve the parent, may not always be facilitated. Such infectious disease measures are problematic and disruptive to the family and are completely incongruent with the ethos of FCC. It is timely to consider examining what the experiences and needs of hospitalised children are in the absence of extended family members and visitors, who act as a distraction and a source of enjoyment for both the hospitalised child and their parent.

6.3 Parents helping me and advocating for me / Parents advocating for their child in hospital

This major category was evident from the children's and parents' data. The children described how their parents' presence helped them to do what they were unable to do for themselves. They described their parents performing advocating activities by speaking to the healthcare professionals on their behalf about the management of their symptoms and treatment plans. It appeared that they understood the importance of this aspect of their parents' role. Equally many parents described their role in hospital with their sick child as that of representing them, or acting as an advocate for them. Often parents believed their child was unable to speak to the healthcare professionals on their own behalf, and it was important to them to be present to do that for their child.

The role of parents as advocates for their hospitalised child has been reported widely in the nursing literature over many years. This is not surprising given the protective nature of the parent-child relationship, and the perceived vulnerability of children. This vulnerability is more pronounced when the child is in hospital, and even more so during a pandemic with significant restrictions in place. Browne and Richie (1990) concurred with this finding in a qualitative study which explored nurses' perceptions of parent and nurse roles in caring for hospitalised children in a tertiary children's hospital in Canada. The nurses believed parents acted as advocates for their children more than the nurses did, to ensure their child received the best care possible. Simons and Roberson (2002) reported similar findings from a phenomenological study conducted in a tertiary referral hospital in the UK, in which they explored parental involvement in care in the context of managing their child's post-operative pain. These researchers found that advocating was a key parental role when in hospital with their child.

Coyne and Kirwan (2012) also supported this finding when they found that some children prefer their parent to speak with the professionals on their behalf, because they felt they were not yet ready to make such important decisions on their own. Livesley and Long (2013) concurred when they found that hospitalised children struggled to have their voice heard. When children felt they were not being listened to, they relied on a supportive adult to speak out and act on their behalf. These researchers concluded that in the absence of a supportive adult, hospitalised children became "marooned on their beds" (Livesley and Long, 2013: p. 1301) with their needs often being overlooked. Coyne (2013) contends that parents' role is one of advocacy while in hospital with their child, reporting that children rely on their parents to advocate for them with the nurses and doctors. Giambra *et al* (2014) also concurred in their grounded theory study conducted in the USA when they reported that advocating was a key role of parents when in hospital with their child. These researchers also recognised that parents' ability to advocate effectively for their hospitalised

child was dependent on the parents' own previous experience of being in hospital, either with their child or themselves. The frequency of education they had received from nurses was also a contributing factor. Watts *et al* (2014) had similar findings in their systematic review of qualitative studies in which they recognised that when parents are present with their child in hospital they ensure their child receives high-quality, appropriate and safe care.

A key role of parents in a study by Vasey *et al* (2019) was that of parents acting as advocates for effective pain management for their child when they perceived their child's pain was not being optimally managed. Similarly, a recent meta-aggregation review exploring how parents of children with a long term condition experience partnership in nursing care (Barrett *et al*, 2021) found that parents valued effective communication and collaborative working arrangements which recognised the skills and expertise of both parents and nurses in planning their child's care. Parents advocated for their hospitalised children until they were confident that their child was receiving optimal care (Barrett *et al*, 2021).

The role of the parent as advocate was not explicitly listed as one of the cornerstones of FCC in a literature review of qualitative studies on the topic (Shields *et al*, 2006), in a systematic review of qualitative studies on FCC for hospitalised children (Watts *et al*, 2014) or in a concept analysis of FCC for children and young people in hospital (O'Connor *et al*, 2019). It could be argued that the development of respectful and trusting partnerships between nurses and families, and parents' desire to participate in care, encompass advocating activities. It is known that parents who are better informed about their child's treatment plan are empowered to advocate with greater effect for their child, and those who have had education from nurses were able to advocate more effectively (Giambra *et al*, 2014).

The parents in this study seemed to feel obliged to be assertive and to advocate strongly for their child in order that they received timely and optimum care from all members of the multidisciplinary team. The children spoke about their unwillingness to speak to doctors or nurses to seek pain relief or other treatment. This has been described in the literature previously (Coyne, 2013; Livesley and Long, 2013). Nurses must support parents when they are seeking help for their child and advocating for them, in this way nurses are empowering parents to advocate in the best possible way for their child's needs and their own concerns. Howlin (2008) asserts that sharing information with parents and children is central to effective advocacy in children's nursing. In a systematic review of the impact of critical illness and injury on families Abela *et al* (2020) found that the most common need of parents was to be well-informed of their child's illness and response to treatment. Curtis and Northcott (2017) contend that parents actively advocate for their children and participate in their care while in hospital without needing to be told to do so. Nurses must

provide easy to understand information to parents about their child's care frequently and include them in all aspects of care planning and decision-making.

Likewise, children's ability to advocate for themselves must also be nurtured. Healthcare professionals do not always empower children to make their own healthcare decisions, frequently decisions are made based on what the healthcare professionals believe the family needs (Shields *et al*, 2018). Allan and Lunders (2021) found that children and young people have clear views and opinions which they will share freely with healthcare professionals when consulted in a respectful and age-appropriate manner. They contend that children and young people can be supported to develop the skills of self-advocacy when they are included in discussions with healthcare professionals on an equal basis (Allan and Lunders, 2021). Healthcare and other professionals must listen to children and take their opinions seriously in order for them to influence the development of services affecting them. The nursing education curricula for children's nurses already includes advocacy, both the role of the nurse as advocate and the parent as advocate. Nurse educators delivering continuous professional development (CPD) programmes must question why the promotion of advocacy through information sharing, both the parent as advocate and children as advocates for themselves, continues to be problematic. The importance of the nurses' role in sharing information in a timely manner and in language that the family can easily understand must be explicitly included in ongoing professional education and training programmes for nurses throughout their careers. Information that parents and children understand will support them to participate in all healthcare decisions.

6.4 Parental roles and responsibilities evolving in an *ad hoc* manner with limited negotiation with nurses

Parents described a lack of formal negotiation with the nurses about their role, claiming that it led to their roles and responsibilities evolving in an *ad hoc* manner over time, with limited formal guidance, planning or agreement with the nursing staff. Many parents found out what was appropriate to do for their child from other parents, some mentioned that they assumed they were doing things correctly because nobody had told them otherwise.

The absence of formal planned negotiation between parents and nurses on their roles and responsibilities has been repeatedly identified in FCC studies over three decades or more. More than thirty years ago in the UK, Callery and Smith (1991) supported this finding in a study which examined the role of negotiation between parents and nurses in hospital. They reported that nurses were in a stronger position than the parent to initiate negotiating conversations because they were in a familiar environment, while parents were away from home and had the added worry of having a sick child in hospital. Darbyshire (1992) explored the lived experiences of parents who stayed with their child in hospital, the nurses'

understanding of resident parents and the nature of the relationship between the two. Darbyshire's study was conducted in Scotland and found that parents believed participating in the care of their child in hospital was unplanned and without any formal negotiation with the nurses. Coyne's (1995) research examining parents' willingness to participate in the care of their hospitalised child also supports this finding. Coyne's (1995) research examining parents' willingness to participate in the care of their hospitalised child found that parental involvement in care was not negotiated with the nurses, rather it evolved in an unplanned way. Similarly, Coyne (1996) in a concept analysis of parent participation in care claimed nurses assumed, rather than planned, that parents will participate extensively in the care of their child in hospital.

Later Kirk (2001) reported that parents believed nurses did not explicitly negotiate roles and responsibilities with them, and so it was unclear to the parents what they should or should not be doing. Kirk's (2001) study was conducted in the UK and examined how healthcare professionals negotiated care with parents of children with complex care needs. Role negotiation became evident only after initial discharge, when parents had some experience of caring for their child at home and of interacting with the nurses. Likewise, in a literature review examining how children's nurses negotiate with parents about FCC (Corlett and Twycross, 2006), it was found that nurses did not routinely negotiate care with parents, and that this lack of negotiation led to limitations in how involved the parents could be in their child's care. A study by Avis and Reardon (2008) also support this finding. They interviewed 12 parents of children with additional needs who had been in-patients in an acute hospital in the UK. These researchers identified that parental involvement in care tended to be expected and assumed rather than negotiated and planned.

Uhl *et al's* (2013) findings were also in keeping with those of this study. They carried out a mixed-methods descriptive study in the USA examining parents' experiences during their child's hospitalisation and reported that a lack of communication with the nursing staff about parents' participation in their child's care had a negative impact on their experiences. Parents believed that accurate and timely information about their child's condition and treatment was important in building and maintaining confidence in their child's care (Uhl *et al*, 2013). Coyne (2013) examined FCC from families' and nurses' perspectives in Ireland and found very little evidence of role negotiation which left parents feeling abandoned, unsupported and undervalued. Similarly the findings of Watts *et al* (2014) are also consistent with these findings; they reported that role negotiation with parents about their participation in care was a difficulty associated with FCC, and frequently did not happen. More recently Foster and Whitehead (2017) concluded that nursing staff must develop the skills of good communication and negotiation in order to provide effective care for the child and support for the parents, claiming that a failure to communicate and negotiate effectively

can lead to role confusion. In a systematic review of the impact of critical illness and injury on families Abela *et al* (2020) found that the most common need of parents when their child was in PICU was to be well-informed of their child's illness and response to treatment.

Vasey *et al* (2018) also found that nurses did not negotiate with parents about their child's pain management plan. These researchers contend that there is often an assumption that nurses do not need to negotiate roles with parents as parents already know what is expected of them when they are in hospital with their child. Recently, in an integrative review of the implementation of FCC for hospitalised children and their families in developing countries (Phiri *et al*, 2020), negotiation with parents remains key to partnership formation between families and nurses. Consistent with the findings of this study, poor communication and negotiation between nurses and families about their child's treatment plans was recognised as a barrier to effective implementation of FCC in practice (Phiri *et al*, 2020). In line with the findings of this study parents in a study by Phiri *et al* (2020) in Malawi described nurses delegating tasks to them without discussion which left them feeling unprepared for the role. The researchers concluded that parents receive inadequate information from nurses and that there is inadequate role negotiation with parents when they are in hospital with their child (Phiri *et al*, 2020).

Despite all the difficulties identified with the implementation of FCC it is still considered the model of choice when caring for children in hospital and their families (Al-Motlaq *et al*, 2018). Eleven children's nursing experts from eight countries worldwide participated in a Delphi study which attempted to gain international agreement on a definition of FCC (Al-Motlaq *et al*, 2018). These experts acknowledged that there are valid claims in the literature that FCC is not effective. However, they concluded that:

“There is still no legitimate reason to exclude the FCC model from practice, especially in the absence of any credible alternative” (Al-Motlaq *et al*, 2018: p. 9).

It is evident that good communication and negotiation of care between parents and nurses remains a cornerstone to effective implementation of FCC. Yet despite the evidence outlined above, variation persists about the degree to which nurses negotiate with parents their involvement in the care of their hospitalised child, and thus empower them to participate in care and decision-making in a meaningful way. In failing to formally discuss/negotiate with parents the needs of their hospitalised child and their own needs, nurses are missing the opportunity to educate and empower parents to safely care for their child both in hospital and, following discharge, at home (Uhl *et al*, 2013). A key target in today's healthcare delivery model is to ensure children are in hospital for the shortest time possible, and that parents are supported to care for them safely at home, in a more appropriate environment, thus minimising the risk of contracting a hospital-acquired

infection. Reducing the time spent separated from the rest of the family and interruptions to school attendance are other key targets (Nicholson and Murphy, 2015). When nurses do not plan care with parents, parents are less involved in the hands-on delivery of care that may be needed at home, and the opportunity to acquire these skills may be missed, which can lead to delayed discharge or even re-admission following early discharge. Parental involvement in the child's care while in hospital and satisfaction with nursing care were significantly greater when the child and parent received care that was family-centred (Kuntaros *et al*, 2007). There was also evidence of reduced parental anxiety when some elements of FCC were applied to the care of the critically ill child and family in hospital (Curtis *et al*, 2016; Uhl *et al*, 2013).

In 1995 Darbyshire (1995; p. 31) suggested that while FCC is “a cherished tenet” of children's nursing and “almost above critique”, he advised that an examination of the true meaning of FCC in practice must be undertaken if the term is not to become “a mere *cliché*”. Why, after all this evidence over such a prolonged period, does negotiation by nurses with parents about participation in care of their hospitalised child remain problematic? Callery (1997) proposed a possible reason for this lack of negotiation as being due to the fact that this work is not visible, and there is no formal record of it, which leads to its unpredictable and *ad hoc* nature. As evidenced from the findings of this present study, it appears that nurses continue to fail to negotiate with parents their role and responsibilities while in hospital with their sick child. Not only does the effective implementation of FCC require knowledge, skill and expertise, it also requires nursing time, which is a scarce commodity in today's healthcare environment and has cost implications. Indeed, Balling and McCubbin (2001) reported parents feeling that better care was given at home than in hospital because nurses were too busy to provide optimal care. Additionally, Coyne (2013) asserts that a chronic shortage of nurses, busy workload and increased nursing documentation are contributing factors to nurses' failure to negotiate care with parents.

However, the reduced length of stay may be another contributing factor as the average length of hospital stay for an acutely ill child between one and 14 years old is now approximately 72 hours (Healthcare Pricing Office, 2022), which leads to increased patient throughput and an associated increased nursing workload in terms of admitting the child and parent, and preparing them for safe discharge home. Moreover, children in hospital are likely to be more acutely ill, once they stabilise and it is considered safe to do so, they are discharged to recover fully in the care of their parents at home. Parents calling the clinical area following discharge with worries about their child, and even presenting to the Emergency Department (ED) for management of complications, contributes to the nursing workload. A study by Lim and Ang (2019) which measured the clinical nursing workload in two general wards in a general hospital in Singapore, found that only 12% of nurses' time

was spent on direct patient care activities while 5% was spent answering and making telephone calls. In a study by Rantanen and Umansky (2016) nurses taking telephone calls from patients and families was ranked the fifth most common task after working on the computer, medication, communication and patient checks.

When nurses take the time to educate the parent and child, they will be better prepared for discharge and empowered to deliver safe and effective care at home. Healthcare leaders and senior hospital executives must acknowledge that FCC is not a luxury, rather it is a necessity in the delivery of quality nursing care to children and families. Nurses at the bedside must have the resources needed and be supported to negotiate care with parents through improved communication and education. In doing so, parents will be better prepared for the earliest possible discharge and empowered to care for their child at home safely, which will result in more efficient use of nurses' time, releasing more nursing time to effectively implement FCC in practice. It is likely that the shortage of nursing staff and early discharge have resulted in a busier nursing workload, which may have led to the expectation that a parent will be present at the bedside with their sick child and participate in care without any negotiation. Sharing information and negotiating with parents are central principles of FCC, without them FCC cannot, and does not, occur. If children's nurses continue to neglect these central principles, then the risk of allowing FCC to become "the mere *cliché*" that Darbyshire (1995; p. 31) warned us about is very real.

6.5 Taking care of myself / Doing my own personal care

Many of the children described being able to do their own personal and intimate care, such as going to the bathroom, showering and injecting themselves, as important to them. The idea of a nurse having to help them with such intimate cares was unpleasant and even appeared offensive to some of the adolescents in this study. Even younger children described a desire to be able to do their own intimate care themselves, instead of the nurse or their parent doing that for them.

Research studies have predominately explored the nature of care for the child in hospital from the parents' and/or nurses' perspectives. Consequently, there is limited published empirical research which includes hospitalised children's views of how much they want to be involved in their own care in hospital. Those studies that have included hospitalised children as research participants provide evidence that children experience varying levels of involvement in their own care in hospital. Furthermore, research including the views of hospitalised children is now more than a decade old, there is a dearth of more recent research. Coyne (2006) in a study exploring children's, parents' and nurses' views of participation in care in the UK reported that children wanted more information so that they could better understand their condition and be more involved in their own care. The degree to which the children in Coyne's (2006) study believed they were consulted on their views

and opinions varied considerably. Pelander and Leino-Kilpi (2010) examined 23 school-aged children's best and worst experiences of being in hospital in Finland. They reported that children are likely to be less stressed if their views are considered and they are empowered to take part in their own healthcare. Coyne and Gallagher (2011) interviewed 55 hospitalised children and young people in Ireland to explore their experiences of participation in communication and decision-making. They found that children wanted to be involved in decisions about their healthcare, and that they felt valued and less anxious when they knew what to expect. In a recent integrative systematic review of children with long-term conditions and their experiences of partnership nursing, Barratt *et al* (2022) found that a triadic partnership where the child, the parent and the nurse work together to deliver care and where each person's voice and opinions are valued, leads to more effective care and satisfaction for the child. They claimed that children were less frustrated when they were given knowledge and power over their own health care decisions.

Most of the nursing research which includes children as participants explores their involvement in decision-making about their condition and treatment plan (Hallström and Elander, 2004; Coyne, 2008b; Coyne and Gallagher, 2011; Coyne and Harder, 2011; Lambert *et al*, 2011) rather than their involvement in their own care in hospital. This represents a significant area for further research on the topic, specifically exploring how children and adolescents can be empowered to be involved in their own personal care while in hospital. By explicitly including children as participants in research, rich insights can be illuminated which will inform developing practice and policy.

6.6 Parents helping the nurses

Parents described how busy the nurses were, commenting that their presence and their involvement in care was very helpful to the nursing staff. Some parents expressed the concern that their child would not be properly cared for in hospital if a parent was not present.

The concept of nurses being busy and parents helping them has been described in the children's nursing literature over many years, with some studies claiming that nurses are sometimes too busy to adequately care for hospitalised children due to competing demands on their time and expertise. Hughes (2007) reported that parents felt they had to stay with their child because the nurses were too busy to care for them adequately. Likewise, Coyne and Cowley (2007) found that parents noticed that the nurses were always busy and that some care was left undone. Consequently parents felt they could not confidently rely on the nurses to look after their child, and so felt obliged to stay with their child in hospital. Similarly, Coyne (2013) found that parents believed that their presence was not only helpful to the nursing staff, but it was essential because the nurses were too busy to be available for their child when needed. Parents in Coyne's (2013) study considered their role was to

help the nurses and to make sure that their child was well cared for. In addition, parents' involvement in care was described as “a critical resource” which helps nurses with their busy workload (Coyne, 2013: p. 805). A chronic shortage of nursing staff, increased patient throughput, increased patient acuity resulting in patients requiring greater nursing input, increased technical/medical tasks being undertaken by nurses and a lack of managerial support were cited as reasons why the nurses were so busy (Coyne, 2013). Furthermore, a concept analysis on FCC for children and young people in the acute hospital setting identified that these exact issues were contributing factors to the inconsistent application of a family-centred approach to care in practice (O'Connor *et al*, 2019).

This phenomenon is not confined to Europe. In a study by Lee and Lau (2013) carried out in China, parents of hospitalised children were concerned that their child may not be cared for adequately because the healthcare professionals always appeared busy, which led to stress and anxiety for parents. In a systematic review of qualitative studies parental involvement in care was reported as a benefit to nurses, with parents helping to lessen the nurses' workload by caring for their child in hospital (Watts *et al*, 2014). De Macedo *et al* (2017) concurred with this finding in research conducted in Brazil, they found that nurses viewed parental participation in care as necessary in light of the nursing staff shortages. More recently in a study by Saria *et al* (2019) in Tanzania, parental involvement in direct patient care was described by nurses as helpful in relieving their busy workload, as they claimed a nursing staff shortage was a barrier for them in providing information to parents. The findings of Phiri *et al* (2019) in a study conducted in Malawi are also consistent with this finding. In their study nurses stated that family involvement in care helped to reduce their workload, claiming that there was a shortage of nurses. A similar finding was reported in a study which explored the child's experience of being in hospital from the child's and the nurses' perspectives (Clarke, 2022). She found that the children considered the nurses were too busy and the nurses reported a lack of time to care which challenged the provision of quality nursing care.

If we are to take this research, and previous research on FCC of hospitalised children and their families seriously, there needs to be acknowledgement at hospital executive level of the additional resources needed to support the effective implementation of FCC in practice.

6.7 Parents “making do with” inadequate facilities

Parents expressed their acceptance of less than optimal sleeping, showering and eating arrangements for themselves while they are in hospital with their sick child. All parents were staying with their child more than two nights, and some parents staying more than six weeks. They described feeling exhausted, sometimes in pain and found being in hospital with their child difficult.

This is consistent with findings from a qualitative exploratory study which explored parents' experiences of participation in the care of hospitalised children in Hong Kong (Lam *et al*, 2006). Four major categories were identified, one of which was the provision of facilities for parents while in hospital with their child. While hospital policy claimed to support parents to stay with their sick child, parents described the hospital as being "ill-equipped" to allow them to stay comfortably for long periods (Lam *et al*, 2006: p. 541). On the general paediatric wards the parents were provided with a hard plastic chair beside their child's bed or cot to sleep on during the night. They complained about pain, interrupted sleep and feeling tired. Parents also described less than adequate showering facilities, which meant that parents had to go home if they wanted a shower. Parents in Lam *et al*'s (2006) study also described eating facilities for parents as poor. In Sweden, Anglehoff *et al* (2018) examined sleep quality and mood in parents (N=82) staying with their child in a hospital and found that sleeping arrangements for parents in hospital were inadequate. Eighty families (97%) were accommodated in a single patient room. Despite this, 32 (39%) of parents reported being woken frequently during the night either by the child or the staff delivering care. Forty-six parents (68%) reported experiencing insufficient sleep, which was associated with the parents feeling low, tired, less alert and having reduced concentration during the day. These findings are in keeping with those of this present study.

A study by Fitzgerald (2004) for Children in Hospital Ireland which is a voluntary organisation, identified that families experience significant additional financial costs when a child is in hospital. This research found that these additional costs included food and accommodation for parents, among other expenses. Again Fitzgerald's findings are consistent with those of this study. Despite the report recommending that a scheme be introduced nationally to assist families to meet the non-medical costs linked to being in hospital with a sick child, almost two decades later this proposal has not been progressed by successive governments. Similar findings were also reported by Australian researchers (Siffleet *et al*, 2010), who recommended that parents be provided with a hot meal every day and a space for families to eat together. They also recommended that parents are provided with free car parking. Shields (2016), an internationally respected nursing researcher in the area of FCC, commented that a key problem with FCC is the persistent failure to meet the needs of parents.

More recently, Children in Hospital Ireland published another report titled *Childhood Illness, Financial Stress: The Hidden Costs of Hospital Care for Children* (Children in Hospital Ireland, 2020), in which the challenges parents and families face when they stay with their child in hospital were outlined. Data were collected through an online survey questionnaire (n=318 respondents, mainly parents) and through semi-structured one-to-one interviews with parents (n=10), staff from childhood illness charities (n=7) and hospital social workers

(n=6). The vast majority of parents in this study (86%; n=231) stayed beside their child in the hospital room or ward, as this option did not incur an accommodation fee. In keeping with this present study, sleeping beside the child in the hospital ward involved the parent sleeping on a “yoga mattress” on the floor which had to be removed early every morning to allow the clinical staff access to the child to provide care (Children in Hospital Ireland, 2020). Sleeping on a yoga mattress on the floor is not likely to result in a restful night's sleep, with the additional issue of being disturbed by nurses and other healthcare staff caring for the child during the night. This was also an issue for the parents in the present study, 35% of whom were cared for in multiple occupancy rooms. The “hidden costs” to families when a child is in hospital identified by Children in Hospital Ireland (2020) include travel expenses, car parking costs, accommodation, food and additional childcare costs for other children at home. The authors argue that it is difficult for parents to advocate for themselves on issues of inadequate facilities such as sleeping, eating and showering arrangements, at a time when they are concerned about the health and well-being of their sick child. Parents are likely to prioritise the needs of their sick child above their own needs, spending their time and energy advocating for optimum care and treatment for their child, hence conditions for parents remain inadequate (Children in Hospital Ireland, 2020). According to Angelhoff *et al* (2020) parental sleep deprivation while in hospital with their sick child led to reduced concentration, reduced ability to receive and process information and a lack of energy, and hence a difficulty in making decisions about their child's healthcare during the day. In addition to poor sleep, poor diet and inadequate showering facilities for parents may have an adverse impact on the health and well-being of parents who are staying with their child in hospital, especially those who are staying for an extended period of time.

Despite all the evidence, sleeping, eating and showering facilities for parents who stay with their child in hospital remain sub-optimal as was evident in this present study. With the development of a new tertiary referral children's hospital in Dublin which is to become operational in 2024, conditions for parents are set to improve substantially, as all patients will be accommodated in single rooms except those in critical care areas. Each in-patient room will have a shower room *ensuite* which can be used by the child and the parent, and a single adult bed within every child's room for the parent, which will address the sub-optimal sleeping and showering arrangements for parents. However, there are no plans to provide a daily hot meal for parents. Currently the canteen in the hospital where data for this study were collected closes at 14.00 hours, and is not open at the weekends. There is another café on site which serves cold meals, sandwiches, wraps and rolls until 18.00 hours Monday to Friday and until 17.00hrs at the weekends. Similar limited canteen arrangements are currently in place in the other two children's hospitals in Dublin. It is not yet known what hours the hospital canteen will operate in the new hospital, or what other restaurant facilities will be available. In the current hospitals parents are charged visitors' rates for the food

they purchase in both the hospital canteen and the café. If conditions for parents staying in hospital with their child are to improve in any meaningful way, the availability of a free or subsidised hot healthy meal daily must be considered before the new hospital opens.

6.8 An evolving approach to care of children in hospital

As is evident from this study many researchers have examined the way in which children are cared for in hospital and their parents' involvement in care over many years in many different countries. Issues such as poor communication between healthcare professionals and families, and a failure to meet the needs of parents were identified as key challenges to the effective implementation of FCC (Zhou *et al*, 2012; Watts *et al*, 2014). Corlett and Watson (2014) proposed a fresh look at FCC as a model of care and suggested integrating children's and parents' rights and needs towards a child and family centred model. Foster (2015; p. 5) asserts that an amalgamation of FCC and child-centred care (CCC) be developed to form the Family- and Child-Centred Care (FCCC) model to include the elements of both FCC and CCC “where the family and child are visible, forefront and equal” in the delivery of healthcare. In an article exploring the concept of CCC, Ford *et al* (2018) claimed that in a FCC approach the child can have a passive role with their parents taking the prominent role, whereas in a child-centred approach to care the child is front and centre of all aspects of care and decision-making. These authors acknowledge that children are dependent on their parent to advocate for their rights and support them in obtaining what is in their best interests. They suggest a merging of CCC and FCC, to Child- and Family-Centred Care (CFCC), where the child is given the prominent position and is supported to be an active participant in his/her own healthcare, supported by their parent. Central to this evolving model of care is “that people are not seen in isolation from each other” (Ford *et al*, 2018; p. e42). This position acknowledges that sick children, their parents and the healthcare professionals work together in an interconnected and interdependent way to deliver healthcare that is firstly child-focused, and then family-centred. This model shifts the order of words, and in doing so the order of prominence, by placing the child before the family, so that the child comes first and foremost, while remaining within the family structure. In a scoping review of concepts used in the context of nursing care for hospitalised children, ten concepts were identified (Loureiro *et al*, 2021). Eight of the 21 studies included in the review focused on FCC, indicating that FCC is the most frequently used model. The authors concluded that while a child and family-centered concept was not identified in the review, care centred on the child and family is emerging in more recent research and is more integrated.

From our experiences as a nation during the pandemic, when the people of Ireland worked together to minimise the impact of the COVID-19 on all aspects of our lives, from healthcare and education, to our social lives and our working and professional lives, we have learned

that working together results in better outcomes for all. The mantra of the Department of Health during their public awareness campaigns at that time was “*Níos fearr le chéile*”, which translates from the Irish language as “Better together”. A CFCC approach will require nurses to work “better together” with children and their parents as equal partners, to support their participation in care, to develop respectful trusting partnerships with them, to share relevant information with them in a timely manner and in language they can understand, and to recognise that all the family are affected by the child's illness. Indeed, Dokken *et al* (2015) in a discussion paper describe how the application of the Institute for Patient- and Family-Centered Care's (IPFCC) campaign “*Better Together: Partnering with Families*” promotes the presence of families as equal partners in care in all hospitals. They advise healthcare leaders that ongoing review of policy and practice must continue in order to optimise partnerships with families. Working together in this way will place the child and family at the front and centre of all that we do, with better outcomes being achieved for all by working better together.

6.9 Chapter summary

In this chapter the findings of the study were discussed in the context of the existing literature on the topic. The emergent explanatory theory was outlined. The contribution to our existing knowledge on the care of hospitalised children and their parents was also discussed and an evolving approach to care of children in hospital was presented. In the next and final chapter the resulting recommendations for education, practice, research and policy will be outlined. The plans for dissemination of the learnings from the study will be presented. The strengths, limitations and the trustworthiness of the study will be presented. Finally, a reflexive account of my research journey will be described.

Chapter 7

Implications and Recommendations, Strengths and limitations and the researcher's reflexive account.

“A child and family-centred care philosophy that integrates both positions and perspectives is required to facilitate positive health outcomes that honor ... the child, parent and family.” (Foster and Shields, 2020)

7.1 Introduction

In this chapter the recommendations/implications for practice, education, research and policy arising from this study are presented. The dissemination plan is outlined. The study's strengths and limitations are acknowledged, and the trustworthiness of the study presented. Finally, I will present a reflexive account of my research journey.

7.2 Implications / Recommendations

7.2.1 Implications for education

7.2.1.1 Ongoing education on CFCC for registered nurses

The findings revealed that parents want to participate in the care of their child in hospital. In order to do so safely, parents must receive appropriate education, advice and support regarding what care is appropriate for them to do. The nurse caring for the hospitalised child is best placed to provide this education and advice for each individual parent and child. A relationship of trust and mutual respect must be developed between the nurse, the child and the parent in order to identify their existing knowledge and skill base and how much they want to participate in care. According to the Nursing and Midwifery Board of Ireland (2018, p. 10) children's nursing is child- and family-centred "where negotiation of care and participation in care is [*sic*] central to a partnership approach to care with families." A true partnership relationship, which recognises the parents' knowledge and expertise, is developed by nurses who practice open and honest communication and negotiation skills with both the children and their parents as partners in care, promoting child and family participation and empowerment in their own healthcare. If nurses take the time to educate parents and support them to deliver safe care while they are in hospital, it is reasonable to expect that they will deliver safe and effective care to their child at home following early discharge.

Key to nurses developing the skills of good communication and negotiation is the provision of evidence-based education and skill development at all levels of nursing education. The core elements of CFCC are formally included in the nursing education curricula at both under-graduate and postgraduate levels. However, while children's nurses in Ireland consider that they practice FCC, there is evidence that it is practiced inconsistently (Hughes, 2007; Coyne, 2013; Coyne *et al*, 2013), although these studies are now dated. Furthermore, there is no evidence from an Irish perspective that children's nurses apply a CFCC approach to their care. The inclusion of CFCC as an educational module within the framework of CPD for registered nurses working in children's healthcare must now be considered. Such a programme should include the fundamental elements of CFCC and how they are best applied in practice and could be delivered as an interactive workshop. Because sustained change is a challenge, it is important to provide not only initial education

but also ongoing education as a reminder of the importance of CFCC concepts. Nurses caring for hospitalised children and their parents should attend such a programme on a two or three yearly basis throughout their careers, similar to that in place for child protection and welfare education. Registered nurses are required to engage in CPD to update and maintain their knowledge and skills (Nursing and Midwifery Board of Ireland, 2015). Rostami *et al* (2015b) assert that the provision of educational workshops on FCC for nurses positively changes their attitude and practice. Passionate nursing leadership that provides consistent messages about the importance of CFCC is also key to sustaining change.

In children's healthcare the sick child and his/her family are the unit of care. The implementation of CFCC requires a move away from the professionals controlling the child's healthcare, and the creation of a true partnership with children and their families so that they are empowered to take control of their own health and become active members of the healthcare team. Such an approach will support the implementation of the National Model of Care for Paediatric Healthcare Services in Ireland (Nicholson and Murphy, 2015), by supporting parents to develop the knowledge and skills necessary to manage their child's care safely at home following early discharge or day case surgery. A culture of open, honest and respectful communication with children, parents and families, and the recognition of them as true partners in care must be included at all levels of nursing education programmes. Nursing management and nurse leaders must endorse such endeavours and promote CFCC practices.

7.2.1.2 Ongoing education on advocacy for registered nurses

There is evidence that parents who are informed of their child's treatment plan will be able to advocate more effectively for their child (Giambra *et al*, 2014). Advocacy is a nursing role that is often overlooked, with the pressures of clinical and technical responsibilities taking priority, especially in light of the increased patient acuity. Nurses are best placed to educate parents and support them in their advocacy role. Children's nursing education programmes at undergraduate and post-graduate level currently deliver content on the role of the parent as advocate for their child and the role of the nurse as advocate for hospitalised children and their families. CPD programmes for nurses caring for children must explicitly include the role of the nurse and parent as advocates, and the importance of frequently sharing information with parents and children about the child's condition and treatment. Information that is easy to understand will empower parents to be actively involved in all healthcare decisions, and to advocate as strongly as possible for their child. Building capacity for the child and parents to self-advocate and supporting them to navigate the healthcare system are explicitly listed as national nursing standards for Canadian nurses (Canadian Association of Pediatric Nurses, 2017). The National Strategy for the Future of

Children's Nursing in Ireland 2021-2031 (Children's Health Ireland and the Office of the Nursing and Midwifery Services Director, 2021) proposes the development of advocacy education within a CPD framework in collaboration with the Centre of Children's Nurse Education (CCNE) to support nurses caring for children to develop their role as child and family advocates.

7.2.2 Implications for practice

7.2.2.1 Facilities for parents

Parents in this study described “making do with” less than optimal sleeping, showering and eating conditions while they were in hospital with their child. This concern was expressed in the context of the hospital where the data were collected, which is an old building and is now considered no longer fit for purpose. A new national children's hospital is currently being built, which will share a site with a tertiary adult hospital and with plans to develop a maternity service on the same site. This new hospital will be configured entirely in single rooms, except for critical care areas. All patient rooms will have an *ensuite* and a single adult bed for the parent to use while in hospital with their child. These facilities will mean that sleeping and showering arrangements for parents will be greatly improved once the new hospital becomes operational. However, these facilities do not address the eating arrangements for parents and families. None of the parents in this study received subsidised rates in the hospital canteen, instead they paid visitors' rates for the food they bought. Some parents who are in hospital for an extended period, and who disclose to the healthcare staff that they are finding the financial burden onerous, may be referred to the medical social worker, who may seek exemption for some parents on an individual basis. Furthermore, the hospital canteen is open from Monday to Friday for very limited times only. The hospital café is open seven days a week until 18.00 hours, closing at 17.00 hours at the weekend. Parents cannot buy a hot meal in the hospital once the canteen closes in the early afternoon, and not at all during the weekend. The extra cost of food is inevitably difficult for some families who may be struggling financially. This additional worry adds to an already stressful situation of having a sick child in hospital. If children's health services are to fully endorse and support the philosophy of a child- and family-centred approach to care, then a clear plan supported by the hospital executive team is needed, that will see the introduction of supports for parents, including subsidised charges in the hospital canteen and extended opening times, to allow them to buy a healthy substantial hot or cold meal in the afternoon, at the subsidised rates which the staff enjoy. Such a plan will recognise the parents as partners in care and members of the healthcare team, and go some way towards truly acknowledging the partnership relationship that is central to CFCC.

7.2.3 Implications for research

7.2.3.1 Nursing quality care metric to include the measurement of CFCC

Children's nursing quality care metrics have been developed to allow healthcare providers to measure the contribution nursing makes to patient care, against agreed evidence-based standards. They provide information to healthcare managers on the quality, safety and effectiveness of the nursing interventions measured and the care delivered (Office of the Nursing and Midwifery Services Director/HSE, 2018). Currently there are eight quality care-metrics measured in children's services in Ireland: medication management, nursing care planning, healthcare associated infection prevention, nutrition, pain assessment and management, vital signs monitoring, child and adolescent mental health and discharge planning. Data are collected monthly using an online data collection system. Areas of excellence, areas for improvement and areas of risk are highlighted and action plans developed, as appropriate, to promote continuous quality improvement.

The National Strategy for the Future of Children's Nursing in Ireland 2021-2031 (Children's Health Ireland and the Office of the Nursing and Midwifery Services Director, 2021) recommended the development of a national minimum set of nursing sensitive key performance indicators to support the measurement of the quality of children's nursing care. As a result of this current study it is recommended that evidenced based nurse-sensitive quality care standards be developed to measure the application of child- and family-centred principles to the nursing care of hospitalised children and their parents. The Intellectual Disability services quality care metrics suite includes the measurement of *person-centred communication* and *person-centred planning* as two separate quality care-metrics. The development of similar nursing metrics for children's services, to include such measures as child- and family-centred communication, child- and family-centred negotiation and child- and family-centred care planning will allow for measurement of compliance with the principles of CFCC. Where non-compliance is identified, the development and implementation of a focused action plan will promote improved implementation of CFCC in practice. In this way not only is tangible data generated to inform healthcare management of the standard of nursing practice, but action is also initiated to bring about quality improvements and compliance in future data collection cycles.

7.2.3.2 The impact of being in hospital while restrictions are in place

The emotional burden of isolation from extended family members who are important to the child during the COVID-19 pandemic is not yet known. Further prospective research examining parents' experiences of being in hospital with a sick child while infection control

restrictions are in place must be undertaken. This research must explore the impact of visiting restrictions, limiting parental presence to one parent only and the possible closure of shared social spaces for children and parents, especially for those children who are in hospital for a prolonged period. It is timely to examine the experiences and needs of hospitalised children in the context of being in hospital while there are limitations in play activities, volunteers and family visitors who all act as a distraction and a source of enjoyment for both the child and the parent. Research including the voice of the child will inform future planning and policy development to support the consistent implementation of CFCC for children and parents in hospital. Children and young people are capable of sharing their opinions and views when they are engaged in an age-appropriate and respectful way (Allan and Luders, 2021). The importance of conducting research with children rather than on them has been highlighted by Coyne *et al* (2021). Involving children in the research process researchers must listen to children and recognise their concerns if their voices are to influence children's services and we are to uphold their rights as outlined in the United Nations Convention on the Rights of the Child (UNCRC, 1989).

7.2.4 Implications for policy

7.2.4.1 CFCC as a standing agenda item on a relevant committee

Since there is no internationally accepted definition of FCC or CFCC to guide nursing practice, they are interpreted in different ways depending on the setting and the beliefs and perspectives of individual nurses. Furthermore, there is a wealth of evidence demonstrating the challenges to the consistent implementation of FCC internationally (Murphy and Fealy, 2007; Foster *et al*, 2010; Coyne *et al*, 2011; Smith *et al*, 2015; Feeg *et al*, 2016; Boztepe and Kerimoğlu Yıldız, 2017; Coats *et al*, 2018; Uniacke *et al*, 2018). It is recommended that CFCC and the child's and parent's experience of hospitalisation is a standing agenda item on a relevant committee such as a family experience committee in all hospitals where children are admitted. Such a committee may already be in existence in some hospitals, such as the Family Forum which currently exists in Children's Health Ireland. This committee should be chaired by a senior member the management team and meet at least quarterly. It is recommended that it has multidisciplinary membership, as well as having parents and children who have been service users as members, thus promoting parent and patient engagement. According to Coyne (2013) family membership on hospital committees raises awareness of family needs among healthcare professionals and contributes to a change in practice. Dokken *et al* (2015) note that inviting family members to participate in hospital committees has been a positive development in FCC. Having CFCC as a standing agenda item on a relevant committee with child and parent membership, will promote meaningful involvement of parents and children in their own care

in hospital. The identification of examples of good CFCC practice, and opportunities for improved practice will be a focus of the committee. Shared learning from the experiences of children and parents receiving care and the healthcare professionals will be an objective of this committee.

7.3 Enablers to the implementation of recommendations

7.3.1 Protected reflective time

Protected reflective time is an integral component of supernumerary and internship clinical placements for undergraduate nursing students in Ireland (Nursing and Midwifery Board of Ireland, 2016), and is facilitated within their weekly roster. In the UK professional reflection for nurses and midwives is central to their annual registration with the Nursing and Midwifery Council (Nursing and Midwifery Council, 2015). It is time to consider a similar model for registered nurses caring for children and their families, where they can be facilitated to reflect on their practice and critically question their role in delivering CFCC in its truest form. The introduction of weekly protected reflective time for registered nurses would allow the delivery of short interactive workshops on advocacy and CFCC, among other topics, to enhance the skills of registered nurses delivering nursing care to hospitalised children and their families. Such protected reflective time would promote the practice of peer support among registered nurses, which is known to ameliorate the risk of burnout and compassion fatigue associated with long and busy working hours (Pereira *et al*, 2021; Mitchell, 2022). It may also support the wellbeing of nurses and help with nursing staff recruitment and retention, which is a problem for nurse managers today (Mitchell, 2022).

7.3.2 The role of the Healthcare Assistant

Parents helping nurses in the context of the nurses being constantly busy was a recurring concern of parents in this study. Some parents believed that their involvement in care was not only very helpful to the nursing staff, but also that their child may not have been properly cared for if they were not present. The busy nursing workload has been identified as a barrier to effective implementation of FCC in many studies (Coyne and Cowley, 2007; Hughes, 2007; Coyne, 2013; Lee and Lau, 2013; Watts *et al*, 2014; de Macedo *et al*, 2017; Prasopkittikun *et al*, 2019; Saria *et al*, 2019; Phiri, *et al*, 2020). The current shortage of registered nurses to supply the nursing workforce, both nationally (Children's Hospital Group (CHG)/Health Service Executive (HSE), 2018) and internationally (King and Crawford, 2009; Williams, 2012) is well documented. In the Irish context, healthcare assistants (HCAs) equate to approximately 10% of the children's nursing workforce, with the scope of their role varying significantly across services (CHG/HSE, 2018). A report on nurse staffing in children's and young people's health care services in the UK (Williams, 2012) suggested a ratio of 70% registered nursing staff to 30% unregistered support staff.

The role of the HCA must now be developed within a structured education and training framework that will support their knowledge and skill development. Just as the role of the nurse has developed to include specialist and advanced practice, the role of the HCA must be developed in a similar manner to support the nursing team in the delivery of safe and effective child- and family-centred care. The HCA will work under the guidance and supervision of a registered nurse, will release nursing time to concentrate on more advanced nursing skills and will complement, rather than replace, the nursing and other healthcare professional workforce. The registered nurse will continue to co-ordinate care and will be responsible for assessing, planning, implementing and evaluating care. When working as part of a team, the registered nurse, the nursing student and the HCA will work together to deliver high quality direct patient care to hospitalised children and their parents (HSE, 2018). This recommendation is supported in key reports including the National Model of Care of Paediatric Healthcare Services in Ireland (Nicholson and Murphy, 2015), the Children's Services Nursing Workforce Planning National Supply and Demand Exercise (CHG/HSE, 2018), the Review of the Role and Function of Health Care Assistants (HSE, 2018) and the National Strategy for the Future of Children's Nursing in Ireland 2021-2031 (Children's Health Ireland and the Office of the Nursing and Midwifery Services Director, 2021). The role of the HCA in delivering direct clinical care to hospitalised children must be explored, including the development of their clinical knowledge, skills and competencies which will go some way in addressing the busy nursing workload and allow more time for nurses to implement CFCC effectively.

7.4 Dissemination

To date, there have been two publications from this study: O'Connor, S., Brenner, M. and Coyne, I. (2019). Family-centred care of children and young people in the acute hospital setting: A concept analysis. *Journal of Clinical Nursing*, **28**(17-18), 3353-3367. doi:<https://doi.org/10.1111/jocn.14913> and O'Connor, S., Brenner, M. and Coyne, I. (2019). Family first. *World of Irish Nursing and Midwifery*, **27**(8), 48-49. A third manuscript is currently in preparation to include the updated literature review. Following completion of the thesis I plan to prepare a fourth manuscript for publication to include the findings, the development of the theory and recommendations. This will be an important publication to inform others of this work and pave the way for further research to refine this theory.

Aspects of this study have been presented at three conferences as outlined in Table 6.1 below. Two further abstracts have been accepted as oral presentations at national nursing conferences in Cork (April 2023) and Athlone (June 2023). Ongoing presentation of this work will be made at healthcare conferences as appropriate.

Table 7.1 Presentations made

Date	Presentation	Conference
28 th August 2019	Family-centred Care of Children and Young People in the Acute Hospital Setting: A Concept Analysis	The Children's Research Network & National University of Ireland Galway in association with Trinity Research in Childhood Centre, TCD PhD symposium
4 th March 2020	Family-centred care of hospitalised children and young people from the perspective of the child and parents receiving care and the nurses delivering or co-ordinating care: a literature review	Trinity Health and Education International Research Conference at TCD School of Nursing & Midwifery.
25 th / 26 th March 2021	Using Constructivist Grounded Theory methodology to explore children's and parents' experiences and expectations of their roles in hospital.	Grounded Theory Online Troubleshooting Seminar
25 th April 2023	Children's and parents' experiences and expectations of their roles in hospital – A constructivist grounded theory study.	Child and Family Nursing Conference: "Sharing Insights and Empowering Excellence" Cork University Hospital, Cork, Ireland.
1 st June 2023	Children's and parents' experiences and expectations of their roles in hospital.	National Children's Nursing Network, Athlone, Ireland.

These publications and presentations are evidence of the expertise I have acquired on the topic and my commitment to dissemination of the study findings.

7.5 Strengths and limitations of the study

The strengths and limitations of this study are now considered.

7.5.1 Study strengths

From the beginning of this journey I wanted to include the voice of the child and adolescent. I firmly believe that children have the right to express their views, feelings and wishes in all things affecting them as stated by the UNICEF (1989). This study is an example of one which included the voice of children and adolescents from the beginning of data collection through to the final recommendations. Interviewing children, adolescents and their parents allowed me to gain insights into their thoughts, opinions and understanding of their role while in hospital, which in turn enabled them to co-construct meaning with me. Following transcription of each interview recording, I emailed a copy of the transcript to each child and adolescent asking him/her to read it and confirm if it was a true reflection of what was said in the interview. Throughout the write-up of the findings and the discussion chapters I used the participants' language to describe the codes and categories as they were identified. In this way the findings and the recommendations arising from the research were co-constructed with the participants in keeping with constructivist grounded theory methodology. The phrase "Nothing about us without us" is reflective of my commitment to involve children and their parents in all things that are likely to affect them. This commitment

to partnership in the research process is a central tenet of constructivist grounded theory method. It is, I believe, also a central tenet of CFCC.

The HSE National Framework for Governance, Management and Support of Health Research (2021; p. 6) defines Patient and Public Involvement (PPI) in research as “research carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them”. This publication goes on to say that the words involvement, engagement and participation in research can be used interchangeably. Including children, adolescents and parents as participants in research about issues that affect them increases the value, quality and relevance of the research. It contributes to the HSE's vision to involve patients and the public in research where possible and increases the impact of the research (HSE, 2021).

The rigorous application of the research methods and how they are explicitly described in this thesis are further strengths of this study.

7.5.2 Study limitations

This study took place on one acute children's hospital in the Republic of Ireland. The participants were recruited from four general medical/surgical wards in the hospital. As with all qualitative studies, the findings reflect the experiences of the participant population and in the context where data were collected. It is possible that the experiences of the participants in this study may not be applicable to participants in other children's hospitals or units in Ireland or in another country. Other hospitals may operate differently, and will likely have a different work-based culture which will influence how children and their parents experience being in hospital. However, I have demonstrated both in the Critical Literature Review and in the Discussion chapters that the findings were similar to those from other studies, both in Ireland and elsewhere. Furthermore, this study was set in the context of a global pandemic, which must be kept in mind when considering the applicability of the findings for another setting at another time.

Taking into consideration that I introduced myself as a nurse researcher to all the participants in the study, by default I created a power imbalance between the participants and myself. As service users they were in a more vulnerable/less powerful position than I. This may have led to the participants, either consciously or subconsciously, being less forthright with the facts of their experiences, which may have influenced the accuracy of the data gathered. In an effort to minimise this risk, I made it clear in the Participant Information Leaflets, that the content of our conversation would not in any way affect the care or treatment the child or adolescent received, either now or in the future. I also reiterated this fact verbally before each interview and made every effort to make the participants feel safe, at ease and comfortable to share their experiences willingly. However, the fact that I was a nurse researcher and was completing a research project as part of a PhD, was ever present.

Despite a conscious effort by myself and the gatekeepers to recruit a culturally diverse population of children, adolescents and parents, the cohort of participants was not diverse. Firstly, I excluded children who were unable to speak English, because I was unable to secure translation services. At the outset of the data collection phase I spoke with all the clinical nurse managers and clinical nurse education facilitators who acted as gatekeepers on the clinical areas where I was collecting data, and explained to them about the need to include children and parents from culturally diverse backgrounds, including children and parents from the travelling community and those who were not ethnically Irish in origin. In the first instance there were no members of the Irish travelling community as in-patients in the hospital at the times I entered the field to gather data, which explains their absence from the participant population. Furthermore on every occasion I could, when there was a family who were not ethnically Irish on the ward, I took the opportunity to ask them to participate. I managed to recruit two parent participants who were not ethnically Irish. In addition, three children, whose parents were not ethnically Irish, also participated, two of the three children were born in Ireland and so were of Irish origin. On one occasion I approached an adolescent and father who were of African origin and asked them to participate. The father declined on both their behalf saying that his son was in pain and it was not a good time for them. On another occasion there was an adolescent on the ward who was of African origin, however his mother or father was not with him. The voices of people from a non-Irish background are therefore under-represented in this study. As with all qualitative research the findings are embedded in the context where the data **were** gathered, hence readers must consider the applicability of the findings to their settings with these limitations in mind.

Finally, a further limitation of this study was that nurses were not included as research participants. However, nurses and/or healthcare professionals were included as participants in 36 of the 62 studies included in the literature review for this current study. Only five studies included the voice of the child. Furthermore, while some studies (n=17) included the perspectives of both the parent and the nurse/healthcare professional, only one study (Curtis and Northcott, 2017) included the child and parent perspectives. A child's view of the world is different to that of an adult. I believed that it was important to capture children's views and opinions together with that of parents in order to complement eachothers' experiences and expectations of being in hospital. Further research including nurses' views on the role of the hospitalised child in their own care and that of their parent will add to what is now known, in this way the triad perspective of the child, parent and nurse partnership in care will be completed.

7.6 Demonstrating the trustworthiness of the study

All research is subject to scrutiny by the readers, so researchers must be explicit about the measures they take to maintain the rigour of their study. Charmaz (2014; p. 337) advises

that when evaluating a constructivist grounded theory study it is the readers who will “judge the usefulness of our methods by the quality of our final product.” Constructivist grounded theory provides rigorous and systematic methods for data gathering and data analysis (Charmaz, 2014). The methodology applied to the study and the methods used throughout this study are explicitly described in detail in this thesis, which adds to the rigour of the study. Nonetheless, demonstrating the measures taken to ensure the trustworthiness of the study must be explicitly included in the final report. This study was evaluated using the four criteria as outlined by Charmaz (2014): credibility, originality, resonance and usefulness. Researcher reflexivity was also included as it contributed to the trustworthiness of the study.

7.6.1 Credibility

Credibility of the findings depends on the trustworthiness of the research methods used and the ways in which personal bias was addressed (Charmaz, 2014).

During the planning stage of this study I considered the credibility of the chosen methodology and research methods proposed in relation to the research aim and objectives. I read extensively in an effort to increase my knowledge of grounded theory generally, and specifically constructivist grounded theory. I registered with Grounded Theory Online (<https://www.groundedtheoryonline.com/>) and attended a two-day seminar facilitated by grounded theory experts to enhance my understanding of the methodology and associated methods. By rigorously applying the methods of constructivist grounded theory, and by being explicit about how I applied them in this thesis, I believe I enhanced the credibility of the study.

Semi-structured interviews with hospitalised children and their parents allowed me to gain deep insights into what it was like for the participants to be in hospital. The use of a flexible interview guide allowed me to explore cues and leads as I identified them during the interview. Through the process of concurrent data gathering and analysis, the interview guide was reviewed and revised to capture leads I had identified and wanted to follow in subsequent interviews as a result of ongoing analysis. Furthermore, I transcribed each interview verbatim and sent a copy of the transcription to the participant to confirm its content and accuracy.

At all stages of the research journey I met with my research supervisors, two children's nurses working in academia with extensive experience of nursing research. In addition one of my supervisors is an experienced grounded theorist. During these meetings we discussed my analysis of the data frankly, any assumptions I may have had were challenged. These discussions enhanced my interview skills and my ability to collect quality data. My interpretation of the data was critically questioned, and whether other researchers

may have arrived at a similar interpretation was debated. Critical discussions about the research methods used and the emergent theory also contributed to the credibility of the study.

7.6.2 Originality

Originality refers to the degree to which the study offers new insights and adds to or challenges existing knowledge on the topic (Charmaz, 2014).

While I was analysing the data coding was repeatedly reviewed, revised and refined with advice from my supervisors until we all agreed that the best codes and categories had been reached. I was very focused as I entered the coding process, in order to be assured that I was interpreting the data accurately. The use of constant comparative analysis and theoretical sampling allowed me to constantly check that the emergent concepts and categories were aligned with the new raw data, as I continued to collect data until saturation was reached. The same process was used to identify the resultant explanatory theory. These activities ensured that the codes and categories identified were grounded in the participants' data and not a result of my personal preconceived ideas. Through collecting children's and parents' accounts of being in hospital and analysing them in a constructivist way, I have presented findings that provide new insight into children's and parents' experiences and expectations of their roles in hospital. The findings of this study illuminate hospitalised children's and their parents' views, feelings and experiences of being in hospital. How they wish to participate in their own care in hospital was identified.

7.6.3 Resonance

Resonance refers to how the resultant grounded theory makes sense to the participants or to people who share their experiences, offering deeper insights into their lives (Charmaz, 2014).

I used the participants' language to tell their stories in the findings chapter and worked hard to remain faithful to them. In arriving at the final explanatory theory I used direct quotes from the participants, their words formed the codes and categories which eventually formed the explanatory theory. The emergent explanatory theory was discussed informally with parents of hospitalised children to seek their feedback in terms of its resonance and if it reflected their experiences. They were positive in their feedback and commented that the theory reflected their experiences.

7.6.4 Usefulness

Usefulness refers to how the final explanatory theory can be used in everyday practice (Charmaz, 2014).

Once I had arrived at the final theory my supervisors and I discussed it in detail and at length. It was modified and refined following these discussions until finally arriving at the theory "*An advocating companion with parental roles evolving in an ad hoc manner with limited guidance from nurses*". I also spoke with senior colleagues both formally and informally, to seek their feedback on its relevance to their practice. The feedback received was positive and gave assurance that the explanatory theory was relevant to children's nursing practice in Ireland today. Furthermore, from a discussion of the findings in the context of existing literature, it is clear that they are supported by both older and more recent national and international literature. Like other forms of qualitative research, generalisability is not the aim of a constructivist grounded theory study. The readers will determine if the findings can be applied to their practice setting. In order to allow readers to make such a judgement, detailed description of the sample and setting were provided. Additionally, a thick description of the findings was also provided, including the context of where the data were gathered and the child was receiving care. By providing a thick description of the findings, readers will be more easily able to decide if the findings are transferable to their setting. Finally the usefulness of the findings are also evident from the implications for education, practice, research and policy as outlined earlier.

7.6.5 Researcher reflexivity

Researcher bias and personal assumptions can compromise the trustworthiness of the findings as they can impact on data analysis and interpretation (Corbin and Strauss, 2015).

I explicitly acknowledged my personal assumptions early in this study and outlined them in the thesis. I also maintained a reflective journal throughout this research journey, initially noting why I decided to study this topic and problem, then noting my thoughts during each stage of the process. During data collection and analysis I embarked on memoing, recording my thoughts and reactions to the interview data, my interview style, the participants' non-verbal cues and the emerging codes and categories, among other things. In this way my awareness of how I may have been influencing the data was heightened and acknowledged through reflexivity. This self-awareness enhanced the trustworthiness of the study findings. At every stage of the research process I had strong academic supervision and leadership which supported me and challenged me in the decisions I made, especially during data analysis, further enhancing the trustworthiness of the study.

7.7 My reflexive account

Reflexivity is a continuous process of self-reflection on how the researcher's own values, beliefs and experiences influence data analysis and interpretation of the findings (Parahoo, 2014). The researcher comes to the study with personal and professional experience and academic knowledge that he/she cannot be disassociated from. As a result of my personal and professional experiences and my professional knowledge of nursing children and of FCC, I recognised that I had preconceived ideas on how children and their parents were cared for in hospital. These ideas included those founded firstly on my experiences as a children's nurse and secondly as a mother of a hospitalised child. From my experiences as a nurse, I believed I included parents in planning and negotiating care and, where appropriate, I included children in an age-appropriate manner. I had worked on an oncology ward for most of my nursing career and the children and their families became well known to us as they attended the unit over a prolonged period for chemotherapy infusions and for treatment of any associated illness, as a result of chemotherapy. Consequently, we became very familiar with the child and his/her family, and FCC may have been easier to implement in such circumstances. However, I had no real evidence to substantiate my belief. Many years later, I became a mother of a hospitalised child on an acute surgical ward. I expected the nurses to negotiate with me what I should or should not do for my daughter, which did not happen. On embarking on this study and reading widely on the topic, I learned that FCC is not consistently applied, and I began to wonder if I truly did negotiate with the parents of the children in my care, all those years ago. Did I have had a rose-coloured view of how I cared for the children and their families many years earlier? As I gathered data directly from children and parents who were receiving nursing care, by asking these questions of myself, I was opening my mind to all sorts of possibilities within the data. I no longer accepted my view that I had always negotiated with the children and parents in my care what they were happy to do. I began to consider if the empirical research I was reading might be evidence to the contrary.

McGhee *et al* (2007) assert that, through reflexivity the researcher becomes aware of the influence his/her personal and professional knowledge and social background has on the research process and outcome. Therefore, prior to beginning my study I identified my own values, beliefs and assumptions by reflecting on my personal and professional experiences, which led me to understanding my philosophical position. In so doing I was able to critically identify the most suitable methodology for this study, which was also a good fit with my philosophical position. Reflexivity enhanced my understanding of the knowledge I had before embarking on the study, and this allowed me to separate it from the new knowledge gained as a result of my research. As recommended by Charmaz (2014), these influences were explicitly acknowledged throughout this thesis.

Maintaining a research journal, recording field notes and memo writing are fundamental elements of constructivist grounded theory that are based on the principles of reflective thinking (Charmaz and Thornberg, 2020). I kept a research journal in which I recorded the challenges I encountered, particularly while collecting and analysing data, and the actions I took to overcome them. I discussed these challenges with my supervisors as needed. This practice also helped to minimise imposing my personal assumptions on the research process and findings. By engaging in such reflexive activities and including them in the final report, I believe I am adding to the credibility of the findings and the emerging explanatory theory. I also maintained reflexive notes following each interview, noting how I felt the interview had gone, how the participant interacted with me, if he/she was engaging and talkative or reserved and quiet. In the beginning this was the case with two child participants in particular, who were both very young. My journal entry following the interview with Colin (12 year old boy) reads "I'm finding it difficult to extract meaningful conversation from some young children, sometimes it's like "pulling teeth"!" Following the interview with Dora (nine year old girl) reads "I felt like I was dragging information out of her". On reviewing my journal entries following Round One of data gathering, I decided that I needed to seek children who were less reticent and would likely articulate their experiences more willingly. After one interview with a mother of an adolescent who was in hospital for a prolonged time, I noted that she had gone off track frequently during the interview. My journal entry following that interview reads "Irene appeared stressed due to the financial stress she seems to be under as a single Mum in hospital without any income for more than six weeks." After the interview was complete and the recorder was turned off, I spoke with Irene about supports that she could access in the hospital that might help her. Reflecting on how the interview had proceeded later that evening I noted that Irene needed to express her frustrations with the system, and that while the interview didn't yield rich insights in terms of what cares she wanted to be involved in when in hospital with her daughter, I did understand that this may have been an opportunity for her to "off load" some stress she was burdened with. Charmaz's (2014; p. 66) advice came to mind when she warns that the participant's comfort always trumps above the researcher pursuing "juicy data". My use of memos throughout the study demonstrate how they contributed to my analytic thinking, to data analysis and ultimately to the emergent theory.

While recruiting and interviewing participants I was acutely aware of the potential for power dynamics throughout the data gathering process. I was aware of the impact my presence in their "hospital space" may have had on the data gathered. I was a professional and was approaching them to partake in "my" research. I was aware they may see me as an investigator and/or an expert in the area. In attempting to address this power imbalance, I made it very clear from the first time I met a potential participant that there was no obligation on them to agree to participate, that they would not be disadvantaged in any way if they

chose not to participate, or indeed if they withdrew from the research during the interview. Additionally, they were not required to explain why they had decided not to take part or to withdraw. This information was also included in the Participant Information Leaflets.

Throughout this study I met with my research supervisors regularly, they challenged me with philosophical and methodological questions, which enhanced my reflexive thinking. Critical reflection during data collection and analysis, in consultation with my research supervisors, ensured transparency and guided the inductive and emergent processes of constant comparison analysis. I remained consciously reflexive throughout this research journey, and I was explicit in my writings about my reflections on the methodology and methods employed to carry out the study. This reflexivity is acknowledged in the memos presented in this thesis, which reflect my thinking throughout the process, especially while gathering data, analysing data and interpreting the findings.

Through being reflexive I acknowledged not only how I may have influenced the research findings, but also how the research journey may have influenced me as a professional. Through reflexivity I gained insight into how new knowledge was co-constructed with the children and parents who participated in this study, and how my experiences and knowledge influenced my interpretation of the data. The factors that stimulated me to embark on this study were my personal experiences as a mother of a hospitalised child and my professional knowledge as a practicing children's nurse and clinical educator over many years. Having read extensively on the topic it appears that little has changed over three decades, in terms of nurses negotiating care with parents and children. As a clinical nurse educator I recognise that this is something I can influence by highlighting the importance of and the principles of CFCC to undergraduate and registered nurses working with children. I can also influence my nursing education colleagues to integrate child- and family-centred care in all modules of nursing education at undergraduate, postgraduate and continuous professional development levels.

7.8 Chapter summary

In this concluding chapter the recommendations for education, practice, research and policy resulting from this study were discussed. The plan to disseminate the learnings from this study were presented. The strengths, limitations and the trustworthiness of the study were presented. Finally, a reflexive account of my research journey was described.

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* indicates the 30 publications included in the concept analysis.

† indicates the 45 studies included in the literature review

†† indicates the additional 17 studies included in the literature review following updating of the search in October 2022

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