

How do cultural factors in the
New Zealand context, impact on the delivery
of Family Centred Care in an acute
Paediatric setting?

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Abstract

Family-centred care (FCC) is widely accepted as the preferred method for providing comprehensive and compassionate care for children, young people, and their families and underpins practice values at Kidz First Children's Hospital. Currently, no guidelines, policies, or foundational documents on FCC are available. Therefore, inconsistency is evident in implementing FCC principles. Establishing an FCC charter is an objective of Kidz First Children's Hospital as the organisation recognises its importance in delivering exceptional, safe, and culturally sensitive care for this diverse population. This practice project aimed at identifying the cultural factors that impact and influence family-centred care at Kidz First Hospital. The findings from this project will provide recommendations for action that will inform the development of the FCC charter. The practice project was conducted in two phases; the first phase was a review of literature that followed a moderated version of Arksey and O Malley's (2005) scoping review format. The second phase consisted of a Kidzfirst service environmental evaluation and the development stages of a FCC questionnaire.

The primary findings from the literature review highlighted key elements that contributed to a culturally safe family-centred care context, and these were 'Respect and Dignity', 'Participation' and 'Collaboration'. The environmental audit revealed that Kidzfirst is providing some aspects of care that are in keeping with a FCC model but that there is room for improvement with many aspects and key recommendations identify areas for improvement. Overall, the findings from this practice project, highlight the essential nature of the elements in FCC in the New Zealand context, emphasising the significance of family and culture in a child's life, the imperative of establishing a trusting relationship and promoting a collaborative approach to care coordination and decision-making in a culturally sensitive way.

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Glossary

Table 1. Glossary

Māori word	Definition
Hapū	Subtribe, or to be pregnant.
Hinengaro	Mind
Hui	Meet, Assemble,
Iwi	Tribe
Rongoa	Medicine
Taonga	Treasure, belongings
Tinana	Body
Wairua	Spirit
Whakapapa	Genealogy, continual layering of foundation
Whakawhanaungatanga	Process of establishing relationship
Whānau	Family
Whānau Ora	Healthy families
Whenua	Land

List Of Acronyms

Acronyms	Meaning
ACCH	Association for the Care of Children’s Health
AAP	American Academy of Pediatrics
ASD	Autism Spectrum Disorder
AUTEC	Auckland University of Technology Ethics Committee
CND	Clinical Nurse Director
FCC	Family centred care
FCCQ-R	Family Centered Care Questionnaires
HDEC	Health and Disability Ethics Committee
IPFCC	Institute for Patient- and Family-Centred Care
KFCH	Kidz First Children’s Hospital
MCHB	Maternal and Child Health Bureau
MDT	Multi-Disciplinary team
REDCap	Research Electronic Data Capture
SDH	Social determinants of Health
SLT	Speech Language therapist

Attestation of Authorship

“I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.”

Signed: Date: 01 July 2023

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Overview of Chapters

Chapter 1

Background and Introduction

This chapter will provide the background and context behind this project including nursing care of children and young people, family centred care (FCC) defined, key principles of FCC and clinicians advantages of FCC challenges of implementing FCC, Te Tiriti and health and FCC in Kidz First Children's Hospital.

Chapter 2

This chapter will describe the motivation for this project, the clinical context where this practice project was conducted and the practice project design, which includes a scoping review of literature, an environmental audit, and the development of a questionnaire.

Chapter 3

This chapter will describe the scoping review of the selected literatures and the findings from the literature review.

Chapter 4

This chapter presents the service evaluation and initial step for developing a questionnaire for future research to understand healthcare practitioners' perception of FCC.

Chapter 5

This chapter will give the summary and key recommendations for the FCC Charter.

Chapter 1. Background and Introduction

1.1 Introduction.

Family Centred Care (FCC) is recognised as a universally accepted approach to providing healthcare for children and their families. It aims to plan wraparound care for the child and the entire family (Almasri et al., 2017). While FCC is viewed as the ideal model of care in paediatric services, consistent implementation has been a challenge for healthcare organisations (Kuo et al., 2012). Kidz First Children's Hospital (KFCH), Te Whatu Ora, Counties Manukau, have cited FCC (*Kidz First About Us*) as their underpinning model and framework and have committed to establishing a FCC charter, which is deemed vital for successfully providing high-quality, safe, and culturally inclusive care. Currently, there are no guidelines, policies, or foundational documents on FCC available at KFCH; therefore, analysing the current environment and relevant literature is essential before a FCC charter can be created and implemented. This project aims to set an action plan and recommendations to form a FCC charter for KFCH.

This chapter of the report will provide background information about nursing care of children and young people, how the definitions of FCC developed, and describe the critical components of FCC and clinicians' roles. This chapter will also include the advantages of FCC and the challenges of implementing FCC. Overall, this introductory chapter will provide a view of the background information and context that led to this project.

1.2 Nursing care of children and young people

The concept of FCC as a mode of care delivery in the context of children and young people's nursing was introduced four decades ago (Johnson, 1990). Before FCC, as recently as the mid- 20th century, no or minimal family member visitors were allowed in hospitals and children were nursed in sterile open wards (Johnson, 1990; Jolley, 2007; Jolley & Shields, 2009). When children had a condition such as polio, they were often institutionalised, and parents had 'little say' and minimal participation in their child's care or even opportunities to visit (Johnson, 1990; Jolley & Shields, 2009). It was in the 1980s that the Association for the Care of Children's Health (ACCH) began to develop programs and information to raise awareness of the importance of family when caring for children (Jonhson, 1990).

One of the earliest and perhaps the first formal definition of FCC appeared in "Family-

Centered Care for Children with Special Health Care Needs” (Shelton et al., 1987). In this article, eight dimensions of FCC were defined, and explanations were given about how each could be implemented in the healthcare setting. The authors of this article described the concept of FCC as being in its “infancy” (p. 54). Since then, FCC has become increasingly ingrained in paediatric nursing care, with institutions and organisations creating new definitions and adapting key principles of FCC into care delivery.

1.3 Family centred care defined.

Family Centered Care (FCC) has been the prominent model of care in children’s hospitals for several decades and is considered the cornerstone and best practice in delivering care for paediatric patients (Almasri et al., 2017). FCC is made up of a set of values, attitudes, and approaches to providing care for children and their family and has been defined in a variety of ways (Kokorelias et al., 2019). It has been described as an approach to healthcare delivery, that acknowledges the principles of partnership with the entire family in addressing the medical and psychosocial health of patients, most often children (Kokorelias et al., 2019).

Other authors have described it 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/person and in which all the family members are recognised as care recipients” (Shields, 2010, p. 2629). These definitions all highlight the importance of a holistic approach to paediatric care that looks to consider the context of the child within the family unit.

According to the Institute for Patient and Family-Centred Care (IPFCC), “patient and family – centred care is working “with” patients and families, rather than just doing “to” or “for them” (Institute for Patient and Family Centered Care, n.d). This idea of working ‘with’ the family is an important one and will be more clearly defined and discussed when considering the core principles of FCC. What is clearly similar across all definitions is the acknowledgement that ‘family’ are the corner stone in a child’s life. The assumption is within the concept of FCC is that when a health care system encompasses the family in planning, delivering, and evaluating the care of a child, the child’s emotional and developmental needs will be met in its fullness (Shields et al., 2012).

1.4 Key principles of Family Centered care

Despite the lack of a consensus surrounding the definition of FCC, there is some agreement about the key principles. Groups such as the Maternal and Child Health Bureau (MCHB), the American Academy of Pediatrics (AAP) and the IPFCC demonstrate similarity in key principles of FCC (Kuo et al., 2012). Kuo et al. (2012) compared FCC principles developed by MCHB, AAP, IPFCC and Cronin/Shaller (Shaller, 2007). (Refer to Table 4). According to Kuo et al. (2012) the general principles shared are:

- Information Sharing: The exchange of information is open, objective, and unbiased.
- Respect and Honouring Differences: The working relationship is marked by respect for diversity, cultural and linguistic traditions, and care preferences.
- Partnership and Collaboration: Medically appropriate decisions that best fit the needs, strengths, values, and abilities of all involved are made together by involved parties, including families at the level they choose.
- Negotiation: The desired outcomes of medical care plans are flexible and not necessarily absolute.
- Care in Context of Family and Community: Direct medical care and decision-making reflect the child within the context of his/her family, home, school, daily activities, and quality of life within the community (p. 298).

Shields et al. (2012) described the nine elements of FCC in the child health literature, which are:

- recognising the family as a constant in the child's life.
- facilitating parent-professional collaboration at all levels of health care.
- honouring the racial, ethnic, cultural, and socio-economic diversity of families.
- recognising family strengths and individuality and respecting different methods of coping.
- sharing complete and unbiased information with families on a continuous basis.
- encouraging and facilitating family-to-family support and networking.
- responding to child and family developmental needs as part of healthcare practices.
- adopting policies and practices that provide families with emotional and financial support.
- designing health care that is flexible, culturally competent, and responsive to family needs (p. 3).

Table 4. Comparison of principles of family- centered care

Categories of principles	MCHB	Institute for Patient- and Family-Centered Care (IPFCC)	AAP and IPFCC Joint statement	Cronin/Shaller	Common principles
Information sharing	Open and objective communication and information sharing Information sharing	Information sharing: complete and unbiased information sharing that is “affirming and useful”	Sharing honest and unbiased information in ways “useful and affirming”	Free flow and accessibility of information	Open and objective information sharing between families and providers
Respect and honouring differences	All respect the skills and expertise brought to relationship. Honours cultural diversity and family traditions	Dignity & respect: honour patient and family perspectives & choices, including knowledge, values, beliefs & cultural backgrounds	Respect for patient needs and preferences. Sensitivity to nonmedical and spiritual dimensions	Mutual respect for family preferences, skills, and expertise Sensitivity to Cultural & spiritual dimension	
Partnership and collaboration	Families and professionals work together in best interests of child and family, with child assuming a partnership role as s/he grows; there is an individual and developmental approach. Partnership between families and professional is the foundation of FCC.	Participation: patients and families encouraged and supported in participating in care and decision making at the level they choose.	Collaborating with families at all levels of health care, in the care of child, professional education, policy making, and program development. Support and facilitate choice about approaches to care and support. Providing/ensuring formal and informal support for patient and family at all ages.	Collaboration and team management, Education/ shared knowledge	Partnership and collaboration in decision making, meeting the needs, strengths, values, and abilities of all. Decisions are made including families at the level they choose
Negotiation	Participants make decisions together. There is a willingness to negotiate. Trust is acknowledged as fundamental		Empowering families to discover their own strengths, build confidence and make choices and decisions about their health.	Involvement of family and friends.	Partnership and collaboration between team members.
Care in Context of Family and community	Develops policies, practices, and systems that are family- friendly/ centered in all settings. Recognizes importance of community- based services	Patients & families included on an institution-wide basis -program development, implementation, and evaluation, facility design, & professional education	Flexibility in organization policies, procedures, & practices so services tailored to needs, beliefs, and cultural values of child and family		Incorporation of families at all levels of care, including encounter, institution, and policy settings.

There is evidence from recent studies that the above principles and key elements are widely accepted and discussed. For example, McCarthy and Guerin (2021) acknowledge that when providing FCC care in paediatrics, the above principles and critical elements must be considered rather than delivering routine interventions and treatment. Kokorelias et al. (2019) found that the FCC model enhances communication and information sharing and creates insight into family, patient, and healthcare professionals when developing care plans. FCC is introduced as a partnership approach to health care, where a child's well-being and desired care will be strengthened when professionals and healthcare providers collaborate effectively with the family (McCarthy & Guerin, 2021). The four primary concepts of FCC are dignity and respect, information sharing, participation, and collaboration (Hill et al., 2018).

1.5 Family centered care and clinicians

In a FCC approach, healthcare providers design the care of a child ideally in collaboration with the family, considering the family's cultural background, strengths, and weaknesses, needs, and coping mechanisms (O'Connor et al., 2019). In other words, a central tenet is to recognise and embrace all family members when planning care for a sick child. To provide this optimal care, clinicians must understand FCC and its key elements and apply them in their practice. According to Kuo et al. (2012), healthcare practitioners in hospitals widely acknowledge the importance of FCC in refining patient health, satisfaction, and healthcare quality and see FCC as a gold standard of child health care. Healthcare practitioners, including doctors and nurses, acknowledge the significance of a FCC approach in improving children and adolescents developmental, social, and emotional needs (American Academy of Paediatrics and Institute for Patient-and and Family Centered Care, 2012; Kuo et al., 2012; Smith et al., 2015).

O'Connor et al. (2019) emphasise that clinicians must comprehensively understand the vital components of FCC to implement it in their practice successfully. When health professionals misinterpret the concepts of FCC, inconsistency is apparent in implementing family-centred care. Despite paediatric nurses widely accepting the concepts of FCC and being aware of its importance, there is a scarcity of empirical evidence to prove its implementation (Coyne, 2013). FCC has been investigated as care directed by parents, with the nurse functioning as a consultant and promoting open and honest communication with the family (Marcellus & MacKinnon, 2016). In order to practice in a family-centred way, the direction of health services must change from one

that prioritises professionals to one that recognises family engagement and working in collaboration as crucial to the child's care and decision-making (MacKean et al., 2005). According to this perspective, families are asked to actively engage in the decision-making, planning, and provision of their child's care to the degree they wish, with the healthcare practitioner serving as an equal partner and facilitator of care (Brodsgaard et al., 2019; Ridgway et al., 2020).

Organisational guidelines and policies can be helpful and developing a conceptual framework and strategy in collaboration with the stakeholders can support the provision of optimal FCC for sick children (Kafulafula et al., 2019; Kokorelias et al., 2019). Davidson and Zisook (2017) strongly recommend that when a patient is critically ill, the clinicians must support the whole family during their adaptation period. Working in partnership with the patient and their families and involving them in decision-making, treating them with respect and dignity, collaborating in policy making and professional education, and delivering care upsurges the quality of care and patient satisfaction (Park et al., 2018). Therefore, health professionals' knowledge and skills to work with these families are vital. Embedding FCC concepts in delivering a high level of care for paediatric patients can potentially enhance their health outcomes (Park et al., 2018).

1.6 Advantages of FCC

The core principle of FCC is to improve the well-being of the patients and the entire family. There is evidence from conventional settings that family-centred interventions can lead to reduced depression rates and caregiver burden, enhanced quality of life for the entire family, and increased satisfaction with care (Crespo et al., 2016; McCalman et al., 2017). In addition, FCC can increase the effectiveness and efficiency of health services at a lower cost (Bamm & Rosenbaum, 2008).

A concept synthesis by Smith et al. (2012) points out that the FCC approach enhances the formation of a trusting relationship between healthcare workers and families for negotiating the care plan and care delivery for the child. Implementing FCC in child's care helps the family understand the importance of care needs, improves the family and child's attachments, and uses available resources which will then enhance child's health outcome (Cinar et al., 2023). Altered regulations in visiting policies will enable parents and extended family to visit and participate in the child's care. Greater patient and family happiness are the result, as well as improved health outcomes and wiser resource allocation (Ebrahimi et al., 2021).

1.7 Challenges of implementing FCC

As previously described, FCC is an approach for delivering high-quality and safe care for children, young people, and their families, yet its implementation is inconsistent for various reasons. In the early 1990's scholars such as Darbyshire (1995) explored some of the challenges that healthcare professionals and, families themselves, had with implementing FCC. Darbyshire's study summarised the major three issues firstly, parents and families are constructed socially within the environment of paediatric wards, secondly, identifying who is the genuine family members and thirdly, having difficulty to understand whose space the pediatric ward is. The concepts explored draw attention to the complexity of nurse-family relationships and of practising family-centred care (Darbyshire, 1995). Further studies by (Hughes, 2007; Feeg et al. 2018) mention that nurses' and parents' disagreement and clinicians' perceptions according to their experience were the common reasons for making FCC implementation difficult.

Authors like Shields, (2010) noted that health professionals needed to show more loyalty to the key principles of the FCC, and when they didn't this made implementation difficult. One of the challenges that healthcare practitioners face is difficulty collaborating with the family. Often it is parents' lack of information that prohibit them from participating in their hospitalised child's care especially regarding decisions on treatment plans (Dall'Oglio et al., 2018). Another factor is insufficient resources, information, and foundational documents, that enable health professionals to develop competence and clarity, and thus support for FCC (Coyne et al., 2011). In addition, a clinician's lack of knowledge and cultural competence is another factor that can cause inconsistencies. An inconsistent FCC practice may result in many unfavourable outcomes, including patient discontent, patient deterioration, a decline in quality of care and an overall effect which leads to prolonged admission (Adcock et al., 2021). Even though FCC is widely accepted and endorsed in the philosophies of care delivery in paediatric hospitals, its execution in clinical practice is often described as challenging and inadequate (Kuo et al., 2012). According to Coyne (2013), the common reasons for the inconsistency in implementing FCC are knowledge and skill deficit, insufficient resources and documents, difficulty negotiating care and failure to collaborate with patients and family. When nurses articulate an understanding of the key concepts or elements, barriers to implementation still exist due to a lack of organisational and managerial support (Coyne, 2011). Often the healthcare professionals who acknowledge the FCC concept fail to express its characteristics in their clinical practice (O'Connor et al., 2019). Insufficient staffing leads to an increase in the workload, subsequently creating a barricade for implementing FCC (O'Connor et al., 2019). Health literacy plays a vital role when providing FCC. Families with little or no understanding of the patient's medical condition are unlikely to be involved

in patient care and decision-making (Mackie et al., 2018). Additionally, certain cultural beliefs and practices of the families such as considering health professionals as the decision makers can be a barrier when implementing FCC (Boztepe & Yildiz, 2018).

1.8 Te Tiriti and Health

Preceding colonisation, New Zealand's Indigenous Māori maintained their ultimate mental and physical health because of the health structures they had developed and the systems they adapted to suit them, their atmosphere, and communal health concepts (Graham & Masters, 2020). However, this streamlined system was disrupted by colonisation and resulted in health inequity, such as diminished access to healthcare, increased mortality, and morbidity due to inappropriate low-quality care and lack of follow-up (Graham & Masters, 2020). The interaction with settlers had both negative and positive impacts. Some of the negative impacts, such as the use of muskets, tobacco, alcohol, affected the health of indigenous people. Māori also contracted infectious diseases from the settlers (Came & Tudor, 2016). In 1840, Many Māori chiefs initiated a negotiation plan and signed a treaty with the British Crown to advance areas of mutual interest. Te Tiriti O Waitangi is the founding document of New Zealand (Wilson et al., 2021). The second article of Te Tiriti declared Māori authority over Māori affairs and taonga, including health. Despite the promises signed by both parties, settler government breached this policy several times and continue to do so which has resulted in health inequities for Māori (Came & Tudor, 2016).

In 1988 Director -General of Health George Salmond edited a memorandum to all health sectors requiring engagement with Te Tiriti. Thus, Te Tiriti of Waitangi was lawfully registered into mainstream public health disclosure (Came et al., 2016). "The New Zealand Public Health and Disability Amendment Act 2010 the legislation that underpins the current health system requires all health providers to address health inequities and engage with the Treaty of Waitangi" (Came et al., 2016, p. 108). The way in which these reforms and initiatives address health inequities for Māori today continue to be inadequate and an issue that should be front and centre when considering the way health care is delivered for children and their whanau.

1.9 Family centred care in Kidz First children's hospital

Kidz First Children's Hospital (KFCH) serve the culturally diverse population of Counties Manukau. Twenty two percent of Counties Manukau's population are children under the age of 15yrs, 14% of New Zealand's child population. This includes 36% of Māori and 32% of Pacific ethnicities (South Auckland Social Well-being Board, n.d.). Māori and Pacific children and families encounter multiple barriers when accessing services, like transport, cost, discrimination by the health care provider, and inaccessible location of the service (Child health strategy,1998). Overcoming these barriers is often difficult for these families and requires enormous support and resources (Child health strategy,1998).

In KFCH, we see the apparent health inequities in the patients admitted. As per 2018 census, over a third of Counties Manukau population live in socio-economically deprived areas, deciles 9 and 10 (Counties Manukau Health, 2021). Numerous Indigenous families face financial and social determinant pressures, which can impair their capacity to raise their children and can cause psychological anguish, bereavement, drug and alcohol abuse, smoking, and violence (Smylie et al., 2008). Family-centred interventions have the potential to recognise and support Indigenous family functioning, including their communication, maintenance of relationships in healthy ways, decision-making, and problem-solving (McCalman et al., 2017).

The incapability to achieve health equity for indigenous Māori patients is a challenge for the New Zealand health system (Wilson et al., 2021). However, the recent reformation of the health system is a crucial step towards creating a more equitable, accessible, cohesive, and people-centred system that will ultimately improve the health and well-being of all New Zealanders (Health New Zealand, 2022). Te Whatu Ora Counties Manukau's strategic goal for 2025 is to enable equity in access and outcomes for Māori, Pacific and communities with health disparities (Te Whatu Ora, Health NZ, 2020). Ensuring everyone has access to quality healthcare, regardless of income, background, or location, is crucial. Investing in preventative care and addressing the root causes of health disparities can create a system that is truly focused on improving the health outcomes of all individuals. Encouraging and empowering families to participate in their child's care, understanding their health literacy, and providing the health education they need will expectantly turn the vicious cycle into a wellness cycle.

KFCH's shared value recognises that *"family/whanau are constant in the child's/young person's life while services and health professionals change. KFCH's service delivery will partner with the family/whanau. KFCH ensures that children/young people are cared for by health professionals who embrace family/whanau-focused care"* (Kidz First About

Us, n.d.). Even though FCC is endorsed in our KFCH philosophy, its application in clinical practice must be more consistent. Also, there is a lack of clarity about how to apply the FCC approach in our practice. In discussion with colleagues, the current impression about FCC is that we are using the term as a "catchphrase" where we claim to be practising in a family-centred way. However, how this plays out in practice is only sometimes evident.

2.0 Aims of the project.

As stated above Kidzfirst has made a commitment to uphold FCC as its model of care, however, there is lack of resources, supportive education and policies available for clinicians. This project will lead the way to develop an action plan and make recommendations towards the formation of a FCC charter for KFCH.

This project has two phases, the first phase will be to conduct a review of the literature which will focus on the impact and influence of cultural considerations when delivering family centered care. This literature review will be based on the scoping review approach described by Arksey and O'Malley (2005). However, this scoping review did not strictly adhere to all the principles of scoping review as advised by Arksey and O'Malley (2005) given the time frame limitations of this project. This will provide a background to inform the charter, a rationale for a culturally considered approach to family centered care including definitions of the core concepts and inform the development of staff questionnaire about FCC. The second phase includes two parts. The first part will be to undertake a service/environmental evaluation to determine the degree to which KFCH has already incorporated key principles of FCC and determine the areas in which areas progress remains to be made. In the second part the aim will be to work with key stakeholders at KFCH to develop a FCC survey that will explore knowledge and attitudes of clinicians regarding family centered care.

Chapter 2 - Practice Project Design

In this chapter, I will outline my motivation for undertaking this project and provide an outline of the planned two-phase approach to this project. I will describe the steps involved, including the planned activities as part of both phases and outline the amendments required as the project progressed. This project explored FCC perceptions, principles, and practices at Kidz First Children's Hospital to inform the establishment of an FCC charter.

2.1 Motivation for the project

I am an overseas nurse trained in India, and I have been working as a paediatric nurse for the past 27 years. I have worked in India and Kuwait, and for the past 18 years, I have worked in KFCH. Currently, I work as Charge Nurse Manager for KFCH.

As a child health nurse, I have encountered many families facing a devastating time when their child is admitted to the hospital. Uncertainty surrounding their child's condition, lack of information sharing, inability to contribute to their child's care, and inability to meet their cultural needs add psychological and emotional distress within the family. Over the years, on many occasions, I have heard the term "Family-centred care"; however, there is an ambiguity in how I implement this in clinical practice.

Working in three different countries over more than two decades, I have experienced a massive difference between clinical environments where children are cared for by the family versus hospital situations where families only visit once or twice during their admission. I see FCC as a method of delivering quality care that has the potential to gratify the entire family and offer a better health outcome for the child.

2.2 Clinical context in Counties Manukau

Counties Manukau has significant growth in the child population, and according to Counties Manukau Health data, 14% of New Zealand's children live in South Auckland (Counties Manukau Health [CMH], 2018). South Auckland has a diverse population, the majority of patients we care for are Māori and Pacific (CMH, 2018). Over the years working in KFCH, I have had an opportunity to work with many Māori and Pacific families, and in many ways, this has enlightened my view on FCC. I have witnessed wider families' vital and central role in Māori and Pacific peoples through personal observation.

Family is central to the community and a way of life for both Māori and Pacific people. The family group within these cultures comprises more than just the child and one or two parents you may have in front of you (the immediate family) but also wider family members, including those from previous generations. Although Māori and Pacific peoples have some differences in their cultural beliefs surrounding the role of family, they share some similarities regarding intergenerational decision-making and their expectation of holistic care from clinicians.

As an overseas nurse, my journey as a children's nurse in New Zealand was not easy initially, as I had to adapt to the new culture. In my previous workplaces, negotiation of care and decision-making was merely a health care practitioner's choice, and parents obeyed the hierarchical decisions. As we see in New Zealand, extended family members were not involved in the child's care or decision-making. Procedures were informed to patients or families to a limited superficial level, not a detailed explanation. I have modified my culture to accommodate this new one, which took a few years. Subsequently, in my leadership roles, the requirement for collaborating with wider families has become a necessity. However, no policies or guidelines were available in our service to enlighten my knowledge.

When I was positioned into the charge nurse role, KFCH had committed to developing an FCC charter. I saw how my own need for guidance surrounding FCC and the plan for the charter development could be leveraged to develop a suitable practice project. Hence, I set out to explore FCC perceptions, principles, and practices at KFCH to guide the development of the FCC charter. An FCC approach will not only improve the health outcomes for the hospitalised child and whanau, but also provide a much-needed resource and guidance for our diverse workforce on caring for our culturally diverse population at KFCH.

2.3 Methodology

The plan for this project included two phases. Originally the plans for the first phase were to undertake an integrative review of the literature to provide a background to inform the charter, a rationale for a family-centred approach to care, and to define the core FCC concepts (Whittemore & Knaf, 2005). The plan for the second phase was to undertake a service evaluation at KFCH to determine the current state. This second phase aimed to determine the degree to which family-centred approaches are embedded in the current organisational culture. Both phases had the overarching goal of providing recommendations for action that would inform the development of the FCC charter. In the following section, I will describe the methods of each phase.

Method Phase 1 - Literature Review

As part of the original project proposal an integrative review guided by Whitemore and Knafl (2005) was planned. The intention of this was to gather and summarize the existing literature on family-centred care models from inpatient paediatric settings. In addition, I planned to review other existing paediatric FCC models (nationally and internationally) through hospital websites, documents, and guidelines. Due to a lack of literature that focused specifically on FCC models of care, the way in which these were enacted in practice and the need to look at both empirical studies and grey literature, it was decided to change the literature review approach and instead to base the literature review on elements from Arksey and O'Malley's (2005) scoping review format. One of the key reasons for this change was related to discussions within the Kidz First service and with my supervisor surrounding the need to consider a more culturally specific look at FCC literature. It was recognised within the context of KFCH that if we were to write an FCC charter that it needed to include a cultural lens.

Scoping review methodology. This scoping review followed the methodological framework proposed by Arksey and O'Malley (2005). A scoping review was selected as the best methodology because its goals are providing an overview of the key concepts in the existing literature on a topic and to identify gaps in the literature (Arksey and O'Malley, 2005) and given that the body of literature surrounding cultural considerations in the NZ context had yet to be comprehensively explored or adequately mapped (Munn et al., 2018). Scoping reviews allow the researcher to examine the 'landscape' of the literature based on a particular question and are often used to lay the groundwork for a more rigorous review (Armstrong et al., 2011). In the case of this project the scoping review was deemed the best approach given there is limited literature to inform the research question of interest (Hanneke et al. 2017). Arksey and O'Malley (2005) provide a five-step framework for conducting a scoping review which includes:

- Step 1. Identifying the research questions
- Step 2. Identifying relevant studies
- Step 3. Study Selection
- Step 4. Charting the data
- Stage 5. Collating, summarising, and reporting the results.

Step1. Identifying the research question.

While a systematic literature review focuses on answering specific and targeted questions scoping review questions are usually much broader and follow a structure such as 'What does the literature say or what do we know about X (population) or y (intervention) or z(context)? (Hanneke et al., 2017). In fact, Arksey and O'Malley caution against creating an overly specific research question. An important consideration and difference to note between a systematic review and scoping review is that a scoping review does not require a quality assessment of the rigor of studies included (Arksey and O'Malley, 2005). The limitation of this is discussed in the final chapter of this report.

The research question that guided this review was "What is known about the impact and influence of culture within the New Zealand context when delivering family-centred care"?

Step 2. Identifying relevant studies.

In this step Arksey and O'Malley (2005) explain the significance of completing a comprehensive search to identify the previous studies both published and unpublished, related to the research question. This search was completed with the assistance from a librarian at AUT and Ko Awatea library. A search was conducted in both electronic databases, internet, and research registers. Details are included in search strategy.

Search strategy. Between 5th October to 10th October 2022 five databases were searched via the AUT library website. A systematic search was performed using the following databases. CINAHL, EBSCO, OVID, Google Scholar, Google, and Medline. Thesis and grey literature were included in this. The databases were chosen as they all include relevant evidence-based literature in nursing, allied health, and medicine (Toronto & Remington, 2020.) An AUT librarian and Ko Awatea librarian were contacted to ensure a thorough search was performed and studies identified are relevant. Keywords used for this search were 'Culture', 'Family centred care', 'New Zealand', 'Aotearoa', and 'paediatrics AND children AND family'. In addition to key words 'Acute, hospital' helped to narrow the search. At first, the search was limited to the past five years and studies undertaken in acute paediatric settings. However, literature was scarce during that period; therefore, the search was extended to 11 years and included studies done in primary healthcare settings. The initial search yielded twelve articles, one thesis and three reports.

Inclusion criteria. Inclusion criteria were 1) Studies done in New Zealand from 2011 to 2022. 2) Studies that included the search term in the topics or keywords. 3) Studies that included the patients, family and health workers in paediatrics, neonatal units, and community. 4) Studies written only in English. 5) Selected articles highlight specific issues related to the care of children and relationships with family within a cultural lens in Aotearoa. The studies excluded were 1) Combined studies done in Australia, United States, Canada, and New Zealand. 2) Studies or reports that does not give significance to culture.

Step 3. Study selection

Arksey and O'Malley (2005) suggest that two reviewers independently screen all citations against inclusion and exclusion criteria for selecting the literature for review. I initially screened all twelve articles' abstracts and titles, one thesis, and three reports against inclusion and exclusion criteria. After discussing the abstract and inclusion and exclusion criteria with my supervisor, we decided to retrieve full-text documents from 10 articles, one thesis and one report which sounded fit for the study and further review. I then retrieved full-text documents from the AUT library database search and google scholar AUT, and the report was retrieved from the website. After reading the full-text documents, I discussed with my supervisor the studies that will be included in the study. We decided to conclude the search due to time constriction and selected eight literature, one thesis, and one relevant report to this study.

Step 4. Charting the data

Peters et al. (2020) suggests concrete record-keeping in a standardised form or table while extracting data. For this part, I developed a data extraction table that included headings such as author, year, country, design, sample, data collection method, findings, and relevance to the project question (refer to Appendix 1). Peters et al. (2020) also recommend that data extraction include at least two reviewers to reduce the chance of bias and errors. My supervisor validated all extracted data to ensure accuracy.

A descriptive-analytical method was used to extract contextual information from each study (Levac et al., 2010). All the study characteristics were summarised using the descriptive-analytical method to create a high-level outline of research conducted to date on the impact and influence of culture within the New Zealand context when delivering FCC (Levac et al., 2010). The key findings from each study were identified and reviewed multiple times to identify commonalities in findings.

Step 5. Collating, summarising, and reporting the results.

Khalil et al. (2021) recommend that reviewers must understand the research question and subject matter to avoid extracting unnecessary data related to multiple variables. Lack of subject knowledge will find it challenging to locate and find data relevant to answer the research question. I developed a thematic construction to create a narrative explanation of existing literature, as suggested by Arksey and O'Malley (2005). The charted information was then organized thematically under three main themes, each with subordinate themes. These will be described in the findings in chapter three.

Method Phase 2 - Environmental audit and development of survey.

The initial plan for phase 2 was to review clinicians' current knowledge and perception of the core elements of FCC and its application in clinical practice and assess the extent to which the concepts and principles of FCC are currently implemented within KFCH. One of the key planned activities was to survey clinician's perspectives; however, due to challenges with ethical approval and the time limitations of the practice project, this plan was abandoned, and a new phase two was developed that consisted of two parts with a series of activities making up each part. The first part was to undertake a service/environmental evaluation to determine the degree to which KFCH has already incorporated fundamental principles of FCC and determine the areas in which progress remains to be made. In the second part, the aim was to work with key stakeholders at KFCH to develop an FCC survey that will explore the knowledge and attitudes of clinicians regarding family-centered care. In the following section, I will provide more detail about the planned activities part of this phase of the project.

Part 1. Environmental Audit.

Evaluation of the current environment at Kidz First using an environmental assessment tool as per the Institute for Patient and Family Centred Care (<https://www.ipfcc.org/>) was deemed a valuable way of capturing information about the clinical areas, bed spaces and areas where children and whanau inhabit during a hospital stay. Although these tools were developed for Patients and FCC as opposed to FCC, the plan was to modify these existing tools considering the four key components of FCC.

The audit tools address areas such as:

- **Leadership** (Example questions: Do our organization's vision, mission, and philosophy of care statements reflect the principles of family-centred care and promote partnerships with the patients and families it serves? Where is this visible in our environment for families? Is this philosophy visible on our website?)

- **Environment and design** (Example questions could include: Does our hospital's design create positive and welcoming impressions for patients and families? Reflect on the diversity of patients and families served and address their unique needs. Are there private family spaces for our patients? Does the design of our wards reflect the diversity of children and families served and address their unique needs?)
- **Child and Family Access to information and Education** (examples could include: Do patients and their families have easy access (view at any time or receive a copy) to their: Clinical information (e.g., laboratory or diagnostic tests), Daily recording of care (e.g., notes from nurses, doctors, allied health)? Discharge summary? Medical records?)
- **Child and Family Participation in Care and Decision Making.** (Example questions: Are our organization's policies, programs, and staff practice consistent with the view that families are not visitors but instead are viewed as allies for patient health, safety, and well-being? Are patients' and families' cultural and spiritual beliefs and practices respected and incorporated into care planning and decision-making?)
- **Education of leaders and staff** (example question: Do orientation and education programmes prepare staff, students and trainees for family-centred practice and collaboration? Do orientation and education programmes prepare staff or culturally responsive practice?)

Part 2. Development of an electronic questionnaire for future implementation.

Given time constraints and the need to develop a robust questionnaire in collaboration with stakeholders (including Māori and Pacific advisors), the revised plan for this project was to develop a questionnaire to seek locality and ethics approval to undertake the survey in the future. There were several key activities as part of this development process, including the need to:

- a) Explore the literature and familiarise self with existing Family Centered Care Questionnaires -Revised (for example, the FCCQ-R, which is a validated tool that directs respondents to rate which activities they perceive to be necessary for FCC (necessary practice) and to self-report on which activities they believe to be currently present in their practice (current practice) (Coyne et al., 2013)
- b) Identify stakeholders (nurses, doctors, play specialists, pharmacists, speech-language therapists, dieticians, physiotherapists, Māori cultural

advisors, and Pacifica cultural advisors). In addition, talk to statisticians and the quality improvement team at KFCH.

- c) Conduct a formal scoping exercise to clarify goals and identify practical problems (for example, how long will the questionnaire be and how might it be administered)
- d) Decide if an existing instrument can be used or do we need to construct our own.
- e) Explore how questions should be presented?
- f) Explore what the questionnaire should look like and what platform should be used. Explore various platforms such as RedCAP and Survey Monkey
- g) Decide how the sample will be selected.
- h) Explore the approvals required and the process for administering a questionnaire to staff at KFCH.
- i) Consult with stakeholders and advisors on the development of questions.
- j) Develop items/questions.
- k) Conduct a pilot test of the questions.

Finally, if time permitted the plan was to create a draft research proposal that could be presented as a project post-completion of the dissertation.

2.4 Ethical Considerations

Before undertaking this project, I completed a comprehensive and careful check on whether this project required an ethical review. I reviewed the Auckland University of Technology Ethics Committee (AUTEC) guidelines and the Health and Disability Ethics Committee (HDEC) website. Based on the information I obtained from the above sources and the nature of the project and after discussion with the supervisor, a decision was made to not apply for ethics approval. Instead, this was approached as a quality improvement initiative for KFCH, where I work. This decision was made under the impression that no discussion would be made with family members or children. No human tissue would be involved, and no revelation of private health information (as recognised by the health information privacy act 1994). This project plan had already been discussed with the Service Manager, Clinical Director, Quality and Risk Manager and Charge Nurse.

As this project work precedes and provides information for developing a Family Centered Care charter for Kidz First Children's Hospital I decided to check with the Te Whatu Ora Counties Manukau Research team about our hospital policy for carrying out this practice

project. As per their request, I completed the research protocol template and applied it. The project aimed to explore health professionals' perceptions, principles, and practices relating to FCC to inform the establishment of an FCC Charter at KFCH. Based on the findings of this assessment, priorities will be set, and an action plan will be developed for establishing an FCC charter at KFCH. The Research & Evaluation Quality review team advised me to get locality approval and a confidentiality agreement from the supervisor. My supervisor kindly signed the confidentiality agreement and I then applied for Locality approval to Kidz First research Committee as I was planning to audit the Kidz First environment, resources, documents, and online material. I was able to obtain the locality approval prior to the commencement of the second face of the project which I have attached in the Appendix.

Summary

This chapter has described the motivation for this project, the clinical context where this practice project was conducted and the practice project design, which includes a scoping review of literature, an environmental audit, and the development of a questionnaire.

Chapter 3 - Findings of Scoping Review

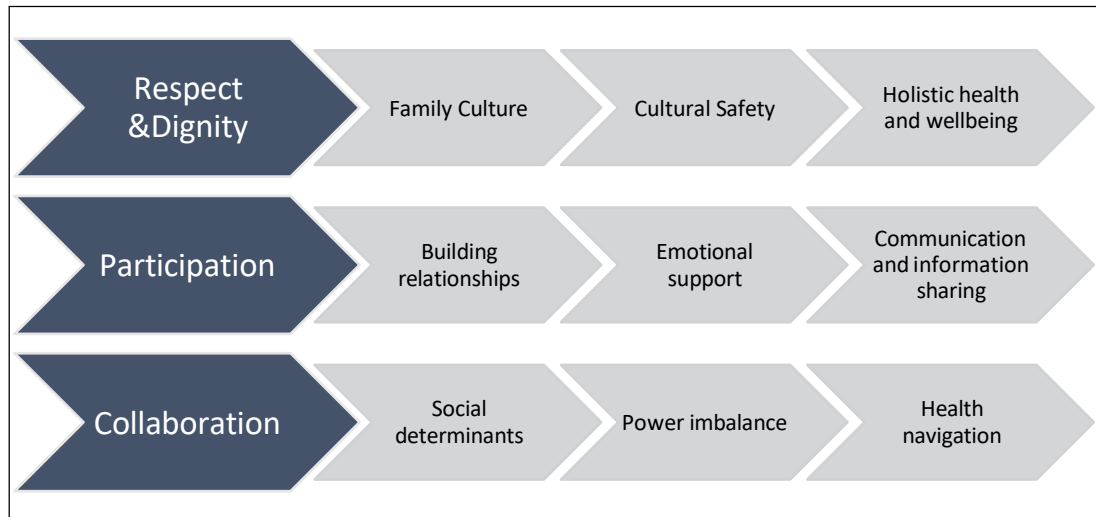
3.1 Introduction.

This chapter reveals the findings in detail of the literature review which is based on a scoping review format (Arksey & O'Malley 2005). Eight articles, one thesis and one report that focused on culture and FCC were selected for the review (Adcock et al., 2021; Crawford et al., 2017; Curtis et al., 2019; Foster & Whitehead, 2017; Graham & Masters-Awatere, 2020; Masters-Awatere & Graham, 2019; Ministry of Māori Development, 2015; Richardson et al., 2017; Tipa et al., 2015; Wilson et al., 2021). All the articles were qualitative studies but varied in terms of the methodological underpinnings. These included a narrative study (Masters-Awatere & Graham, 2019), evaluation (Tipa et al., 2015), Kaupapa Māori (Adcock et al., 2021), qualitative cross-sectional (Foster & Whitehead, 2017), focused ethnography (Crawford et al., 2017), and a systematic literature review (Graham & Masters-Awatere, 2020). Most participants were mothers, family members, patients, nurses, and other healthcare practitioners. Participants' numbers varied anywhere from 10 to 91. All studies were published in New Zealand. The settings were hospitals, the community sector and family homes. All articles were included in this literature review and analysed for prominent themes. The overarching themes identified were 1) Respect and Dignity, 2) Participation, 3) Collaboration.

3.2 Descriptive Overview.

Thematic analysis of the included studies revealed three significant overarching themes and subthemes that emerged from these studies: Respect and Dignity (subthemes included family and culture, culture and safety, holistic health, and wellbeing); Participation (sub-themes included effective communication and information sharing, building relationship, emotional support) Collaboration (subthemes included social determinants, power imbalance and health navigation). These themes are intertwined with the FCC principles discussed in the previous chapter. Please see Figure 1— cultural influences on family-centred care themes.

Figure 1. Cultural influences on family centred care key themes.



3.3 Respect and Dignity

Dignity and Respect was the first major theme identified. Treating children, young people, and their families with respect and dignity is essential to providing holistic family-centred care. The reviewed articles strongly indicated that when treated with respect, dignity, and value, patients and families had more positive health outcomes and increased satisfaction (Adcock et al., 2021; Crawford et al., 2017; Foster & Whitehead, 2017). This central theme is underpinned by three sub-themes highlighting the elements contributing to or working against creating an FCC environment encompassing respect and dignity. The subthemes are 'family and culture', 'cultural safety', and 'holistic health and wellbeing'. All three sub-themes are interrelated and have a significant impact on individual patients' health outcomes as well as contributing to FCC.

3.3 a. Family and Culture.

One central element raised under the first main theme, 'Respect and Dignity', was the significance of family and culture in family-centred care. According to Crawford et al. (2017), family-centred care is a model of care in childcare that provides wraparound holistic care for patients and their family and appraises the family's emotional and physical support. Foster and Whitehead (2017) agree with the above definition and describe a family-centred care model as one that validates the needs of patients and their families holistically and in a culturally appropriate way. Foster and Whitehead (2017) further argue that the family is considered the vital support for children when admitted as they know their children's needs more than the health care professionals.

The combined conclusion of Graham & Masters-Awatere, 2020; Tipa et al., 2015; Wilson et al., 2021 agree with the statement of Foster and Whitehead (2017) that including the whole family in a child's care, encouraging, understanding, and accepting the family's needs will enhance the physical, emotional, psychosocial well-being and satisfaction.

Several articles in this review identified a strong connection between children, family, and culture within the New Zealand context (Adcock et al., 2021; Crawford et al., 2017; Foster & Whitehead, 2017). In Māori culture, children are upheld as the centre of the family; they represent the past and present of their ancestors and hold the future of their Whānau, Hapū, Iwi (tribal groups) and whenua, health, and well-being (Adcock et al., 2021). The evidence from further studies asserts that the importance of family and intergenerational well-being is considered a collective responsibility, where family involvement creates positive outcomes and satisfaction (Graham & Masters-Awatere, 2020; Tipa et al., 2015; Wilson et al., 2021). Adcock et al. (2021) emphasized the importance of the family's connection to a child when caring for them, and this connection came through their whakapapa and spiritual practice.

Whakapapa is the Māori word for genealogy. "The importance of whakapapa in the Māori world is paramount because it is considered crucial to assertions of Māori identity and tribal membership" (Mahuika, 2019 p .1). For Māori families, their ancestors pass on Māori knowledge, and they respect their ancestors' knowledge and belief (Graham & Masters-Awatere, 2020). Adcock et al. (2017) highlight that ancestors pass on their lived experience of parenting skills and these practices are conversed in the family. When healthcare practitioners question these practices, the family network gets destroyed, creating emotional trauma for the new parents. Furthermore, Adcock et al. (2021) reported that Māori families name their children after their ancestors' names and believe in this strong connection to their whakapapa and intergenerational Whakawhanaungatanga (Wilson et al., 2021; Adcock et al., 2021). Families feel culturally disrespected when these names are mispronounced or when healthcare providers avoid these names (Adcock et al., 2021; Graham & Masters-Awatere, 2020; Masters-Awatere & Graham, 2019).

Foster and Whitehead (2017) argue that the family is considered the vital support for children when admitted as they know their children's needs more than the health care professionals. The combined conclusion of Graham and Masters-Awatere, (2020); Tipa et al., (2015); Wilson et al., (2021) agree with the statement of Foster and Whitehead (2017) that including the whole family in a child's care, encouraging, understanding, and accepting the family's needs will enhance the physical, emotional, psychosocial well-being and satisfaction. Multiple authors identify that Māori patients believe the healthcare

system undervalues their spiritual and cultural practices and believe that healthcare providers focus on and prioritise their 'physical needs' but do not consider their mental and spiritual needs (Graham & Masters-Awatere, 2020; Masters- Awatere and Graham, 2019; Tipa et al., 2015; Wilson et al., 2021). When Māori experience discrimination, racism, and bias, they feel health practitioners devalue their spiritual and cultural practices. Subsequently, Māori patients must compromise their cultural and spiritual needs to receive hospital treatment (Graham & Masters-Awatere, 2020). Tipa et al. (2015) suggests that a care delivery model that is culturally safe and responsive is essential to diminish the health discrepancies and inequities for Māori.

Foster and Whitehead further claim that health care staff's understanding of family-centred care, their perceptions, attitudes, and skills influence the ultimate delivery of care (Foster & Whitehead, 2017). Patients and families expect nurses to understand the importance of meeting their unique cultural needs (Crawford et al.,2017). There is evidence from the studies that families feel satisfied and show gratitude when clinicians consider their spiritual needs using Karakia or referring them to cultural support person (Wilson et al., 2021; Adcock et al., 2021). However, healthcare practitioners recognise that the implicit culture of the unit, hospital policies and practices hinder meeting the cultural needs of the patients and the wider family (Crawford et al., 2017; Adcock et al., 2021).

3.3.b. Cultural safety.

Crawford et al. 2017 in their study define culture as “our way of living, . . . activities, ideas, belongings, relationships, what we say, do, think and are . . . an outcome of the influences of ancestors, biology, and philosophy of life” (p. 2). It is evident from the papers reviewed that historically, Māori encounter criticism, marginalisation, racism, and they live in a stigmatised society (Adcock et al., 2021; Wilson et al., 2021). Crawford et al. (2017) define context as "the framework to understand cultural beliefs and practices...includes cognitive, symbolic, structural and environmental elements relevant to a particular setting or situation” (p. 2). Therefore, meeting the cultural needs of a patient and their extended families in the hospital and the community is a vital responsibility of healthcare provider. Wilson et al, (2021) argues therefore, that receiving culturally safe and meaningful care is paramount in achieving health equity for Māori patients.

Curtis et al. 2019 point out that when healthcare practitioners possess an individual perception and belief regarding cultural competency, it fosters a process of "othering" whereby individuals are thought to be distinct from themselves or the dominant culture. This other-focused attitude to cultural competency tends to oversimplify understanding

of different cultures accordant to cultural stereotypes. This stereotype can standardise indigenous people into a collective entity labelled 'they'. When healthcare practitioners have this minimal understanding of culture, they make inaccurate assumptions about individual patients, ultimately impacting the delivery of quality care (Curtis et al., 2019). According to Curtis et al. (2019), achieving cultural competency is a tick box and makes practitioners feel comfortable providing care. They further argue that attaining cultural competency is mainly acquiring knowledge, skills, and attitudes, making it a relatively straightforward and ongoing process.

Cultural safety is described as "a focus on the delivery of quality care through changes in thinking about power relationships and patients' rights" (Ramsden,1996, as cited in Curtis et al., 2019, p.12). Cultural safety enhances the patients' health outcomes by encouraging clinicians to be aware of power imbalances, the impacts of colonisation, and the importance of reflective practice. It also enables patients to identify that their care is culturally safe (Curtis et al., 2019). When healthcare practitioners understand their own cultural practices, biases, attitudes, and stereotypes, they can deliver quality and safe care for their patients without prejudice (Curtis et al., 2019; Tipa et al., 2015).

Curtis et al. (2019) further argue that cultural competency only fosters a generalised and limited understanding of other cultures, making health practitioners make false assumptions about individual patients and not provide the necessary quality of care. There are several areas where healthcare practitioners make assumptions about family, including beliefs, smoking status, parenting skills, and relationships (Adcock et al., 2021). These assumptions can make families feel unsafe and dehumanised.

Cultural safety is an ongoing process of self-reflection focused on critical consciousness (Curtis et al., 2019). Experiencing culturally unsafe care and seeing clinicians practising without cultural understanding negatively impacts families when encountering healthcare services (Adcock et al., 2021). One example is in relation to Rongoa, a traditional medicinal treatment and practice used by Māori (Graham & Masters-Awatere, 2020). The dominance of biomedical practice in health care often prevents Māori from using these traditional treatments as they are scared and embarrassed to discuss this with their practitioners. When caring for a Māori patient, understanding the Māori culture and the value and significance of Rongoa in their healing process is essential for a healthcare practitioner (Graham & Masters-Awatere, 2020). At the same time, Adcock et al. (2021) found that families felt culturally safe when practitioners provided wrap-around care and understood the importance of practising their ancestor's knowledge.

3.3 c Holistic health and well-being.

Wairua (spiritual), Whanau (extended family network), hinengaro (the mind) and tinana (physical) are four prime components of Māori holistic health and well-being (Wilson et al., 2021). All four of these elements are interrelated. This contrasts with the Western view of well-being, focusing mainly on physical well-being (Wilson et al., 2021). Most of the authors in this review mentioned Wairua, whānau, and the significance of these concerning intergenerational well-being, which is a collective responsibility (Adcock et al., 2021; Crawford et al., 2017; Foster & Whitehead, 2017; Graham & Masters-Awatere, 2020; Masters- Awatere & Graham, 2019). Compared with the above authors, who mentioned only emotional well-being, Wilson et al. (2021) gives an in-depth view of all four Māori holistic health and well-being components. They describe how understanding and enquiring about a patient and family's spiritual needs respectfully and supporting them, for example, participating with them in a karakia during difficult times, will influence their engagement with healthcare providers (Wilson et al., 2021). According to Wilson et al. (2021), hinengaro denotes a person's mental status, which regulates their expression of feelings, self-esteem, self-respect, and confidence. Wilson further explains that the central point of hinengaro is the essence of life, which the environment can negatively and positively influence. Hinengaro is a concept that refers to the "invisible private thoughts and emotions" (Wilson et al., 2021, p. 6). When questioning Māori, precautions should be taken to avoid direct questions as they may disclose their inner thoughts and feelings, which will then breach a person's sense of privacy. (Wilson et al., 2021).

The Tinana of a person is beheld as very sacred and is thornily connected to Whanau and Whakapapa. It is a protective space for Wairua and hinengaro and a foundation of sustenance for the body and health (Wilson et al., 2021). The health and well-being of Māori are ingrained in relationships and connectedness. Māori view of health is a socio-cultural concept that develops within the family and is formed and cultured over time (Wilson et al., 2021). Wilson et al. (2021) strongly argues that a relational model of care where healthcare practitioners respectfully engage with Māori and incorporate the concepts of health and well-being for Māori in their practices can improve the effectiveness of their interactions. This is evident in the study done by Adcock et al. (2021) when health practitioners showed empathy and respect. Parents and extended families felt the warmth and love, and they felt the homely environment and closer connections. Wilson et al. (2021) further discloses that the current healthcare system in New Zealand is contradictory to a Māori relational-based worldview of health and well-being as it is based on an individualistic, problem-based biomedical approach. Additionally, the authors emphasize how Māori experience their cultural values and spiritual belief are disrupted in hospital settings as the hospital settings tend to favour

dominant European culture. A cultural view and awareness of Māori people's health and well-being will benefit from achieving equitable access to health care.

3.4 Participation

The second theme revolves around participation, which emerges from the involvement of parents and extended family in the child's care. This evident participation has enhanced patient safety, health outcome and patient, family, and health practitioner satisfaction. This central theme encompasses three sub-themes Building Relationships and Trust, Emotional Support, Communication, and information sharing.

3.4 a Building relationship.

“Whakawhanaungatanga” is the term used in Māori for building relationships (Adcock et al., 2021). Adcock et al. (2021) explain how a trusting relationship established by healthcare practitioners in a neonatal setting can make them feel their baby is in safe hands and that safety, love and warmth resonate in the entire family. Health care practitioners, parents and extended family will have feelings of oneness and become a whanau working together for the better health outcome for their preterm baby. On the other hand, parents and extended family felt unsafe and disconnected when they were not included in the baby's care or when health practitioners made assumptions about their ethnicity, smoking status, and skills. (Adcock et al., 2021).

Foster and Whitehead (2017) noticed that healthcare practitioners' defiance, perception and skills could impact family-centred care delivery. A trusting relationship between health care practitioners, patients and families will influence the decision-making and, thus, a positive health outcome for the patient. Crawford et al. (2017) expressed that building relationships with families is vital in shaping nursing practice and improving patient health outcomes. Curtis et al. (2019) claim that cultural safety is about knowing the culture and building connections and relationships between healthcare providers, patients, and families. Such trusted relationships will help healthcare practitioners understand the patients and their social, mental, spiritual, and cultural needs. Tipa et al. (2015) describes that acquiring respectful relationships is pivotal when working with Māori patients; nurses' facial expressions indicate their interest and curiosity towards interacting with the patients. Wilson et al. (2021) strongly agrees with this, as they suggest honest and non-judgemental interactions can create a trusting relationship. Similarly, Graham and Masters-Awatere (2020) stated that when Māori patients develop a positive relationship with healthcare professionals in the community or the hospital, they feel positivity and engage well, thus increasing health outcomes.

There is evidence from the studies that continuity of care is a significant factor that augments the relationship between healthcare professionals and whanau on a social and relational level (Graham & Masters-Awatere, 2020; Adcock et al., 2021). Patients, parents, and extended families prefer to build relationships with limited healthcare professionals as consistency of care is vital for them, and they feel emotionally connected (Adcock et al., 2021; Graham & Masters-Awatere, 2020). Adcock et al. (2015) identified that neonatal parents and families request less staff changeover as the parents do not want to establish a new relationship, and inconsistency in care is evident when a new nurse takes over. When patients and families do not feel warmth in their relationship with the healthcare team or due to high staff turnover, and when they must repeat the questions and explain their medical condition, Māori patients feel disconnected and feel inconsistent care (Graham & Masters-Awatere, 2020). However, researchers have concluded that the hindrance to building this relationship is the busyness of the ward, nurses concentrating on the completion of the task, high turnover of staff and shift change (Graham & Masters-Awatere, 2020; Foster & Whitehead, 2017; Adcock et al., 2021). Foster and Whitehead (2017) relate to this as three shift changes in 24 hours make building the relationship inconvenient and maintaining consistency in answering parents' enquiries.

3.4 b Emotional support.

Children often endure mental trauma which results them to rely on their families and professionals for decision-making, treatment, and emotional and developmental needs (Foster & Whitehead, 2017; Adcock et al., 2021). Hospital admission of a child disrupts the whole family's smooth functioning. As Crawford et al. (2017) identified, parents and families often feel emotional breakdowns, shock, sorrow, remorse, powerlessness, guilt, and anxiety. Additionally, families struggle to have time to prepare food, and they will face financial constraints, and the difficulty of transportation adds complexity to situations. They also feel isolated as they have restricted movements and boundaries and must control their feelings (Crawford et al., 2017).

Parents feel insecure when their babies are admitted; for example, in NICU, some parents are afraid to hold their tiny babies; this is similar in ICU and ward situations where children are connected to multiple pieces of equipment and invasive tubes like nasogastric tubes (Adcock et al., 2021; Crawford et al., 2017; Foster & Whitehead, 2017). Clinicians' advice and direction are pivotal in building their confidence (Adcock et al., 2021). The statement made by Crawford et al. (2021) is agreeable that nurses understand the necessity of emotional support for parents, but their responses will be

informational or instrumental. He further states that this is due to the traditional interpretation that the parents will cope with the situation. When healthcare practitioners show interest in the patient and the entire family and treat them with respect, honesty, warmth, and compassion, it creates a positive outcome for their emotional well-being (Adcock et al., 2021; Graham & Masters-Awatere, 2020).

3.4 c Communication and information sharing

Effective Information sharing and communication play a vital role in healthcare as they facilitate the development of trusting relationships with healthcare practitioners' patients and families (Graham & Masters-Awatere, 2020). Adcock et al., 2021 found that when parents experience an emotional roller coaster and are anxious about their baby's life, providing them with excessive information will be overwhelming. Foster and Whitehead (2017) emphasise the importance of clear, sincere, and respectful communication to deliver family-centred care safely. An open conversation initiated by health care professionals and their listening to the parents and their needs will encourage them to actively participate in deciding their child's treatment. Foster and Whitehead (2017) acknowledge that clear communication increases parental satisfaction. Graham and Masters-Awatere, (2020) assert that when information is presented in pamphlet form, patients often feel they need assistance with comprehending the content, which burdens them to take the initiative to explain it; this is often stressful for the patient and family. Additionally, these actions cause disbelief in the healthcare system, resulting in disengagement with healthcare providers (Graham & Masters-Awatere, 2020). Lack of information sharing is prominent when providing safe, quality patient care. Nonetheless, Graham and Masters-Awatere, 2020 point out that this missed information is due to the unawareness of staff, time constriction or clinician's attitudes towards Māori patients.

A qualitative study by Crawford et al. (2017) points out that communication between nurses and parents is not merely individual skills but irretrievably dependent on the cultural context. Crawford et al. (2017) further argue that communication with parents is mainly informational; nurses feel less confident or unaware of managing difficult communication with the parents. Busyness and heavy workload limit nurses from engaging with their families (Crawford et al., 2017).

3.5 Collaboration

Working in collaboration is the third central theme identified. Three sub-themes emerged 4.1 Social determinants of health, 4.2 Power imbalance 4.3 Health navigation. Coordination of care and advocacy is essential when delivering family-centred care. Healthcare professionals, patients and families working in collaboration foster a sense of collectiveness and responsibility towards the health outcome of children. The collaboration includes sharing knowledge, leveraging diverse perspectives and expertise, and engaging in shared decision-making.

3.5 a Social Determinants of Health (SDH).

Masters- Awatere and Graham (2019) reported that in Aotearoa, Māori whanau live in lower socioeconomic conditions, living in poor housing situations and limited access to healthy food, causing child health problems with poor health outcomes. They further argue that the poor health outcome is not because of a lack of health literacy or health knowledge but rather due to insufficient resources to access (Masters- Awatere & Graham, 2019). When considering family-centred care as the model of care in paediatrics, recognising the importance of social determinants in child health is vital.

When a preterm baby is born, or a child is admitted to a hospital, the entire family's daily life plans are distorted (Adcock et al., 2022; Graham & Masters-Awatere, 2020). Single-earning families lose their income as other partners must leave work to look after the siblings due to the unavailability of childcare, which will then cost financial constraints, lack of food, housing, and transportation issues. The nominal fees in health care facilities in the community is a burden for some families, and they are forced to choose food for living over their sickness (Graham & Masters-Awatere, 2020). Wilson et al. (2021) emphasises that living in lower socioeconomic conditions, inequitable access to health services, and safe, quality health care is the reason for the poor health outcome for Māori. Identifying the SDH and individual needs and referring them to appropriate services and agencies will improve health outcomes (Graham & Masters-Awatere, 2020). Recognising the social determinants of the health of individual patients and families by health care practitioners will help reduce patients' and families' emotional stress. Adcock et al. (2021) show that referring them to social workers for financial support or for arranging transportation will relieve parents' and families' burdens. However, some practitioners take it as an added responsibility and try to avoid such needs raised by patients and families (Crawford et al., 2017; Foster & Whitehead, 2017).

3.5 b Power imbalance.

Curtis et al. (2019) suggest that healthcare organisations must understand the power imbalance between healthcare providers and patients and concede how it impacts clinical efficiency. The evidence from Adcock et al. (2021) shows that parents and extended families feel a lack of autonomy in the neonatal unit as health practitioners take over the care of their infants, and they observed the significant power imbalance between health practitioners and Whanau. Also, extended family members could not support their mother as hospital policies and health professionals did not support them. Adcock et al. (2021) further claim that the power of the health care practitioners created excess emotional stress for the Whanau. In contrast, when healthcare practitioners were supportive and welcoming to the parents and extended Whanau, the power dynamics changed, and they felt autonomy (Adcock et al. (2021).

Nonetheless, Richardson et al. (2016) argue that when nurses practice cultural safety, where they identify their own culture and the power relationship theory, they will use "power with" patients rather than "power on". This means nurses will recognise the power imbalance and utilise their knowledge and skills to educate patients and their families (Richardson et al., 2016). The nurse's cultural belief can influence their interactions with patients and their families (Richardson et al., 2016; Curtis et al., 2019). Māori patients reported they feel scepticism over racism and discrimination (Curtis et al., 2019). Some families feel the hospital atmosphere is hostile and culturally distant (Wilson et al., 2021). Curtis et al. (2019) suggested that healthcare practitioners understand and reflect on their own cultural views, evaluate the taken-for-granted power structures, and make the patients and families identify whether the practitioner's interaction is culturally appropriate will enhance cultural safety in healthcare settings.

3.5.c Healthcare navigation

Healthcare navigation plays a pivotal role in FCC in New Zealand. In an FCC context, healthcare navigation refers to a service that supports and guides individuals and families with information and resources for decision-making and advocacy to navigate the complex healthcare system (Graham & Masters-Awatere, 2020).

"Whānau Ora", which translates to family well-being, is a holistic approach that recognises the interrelation of individuals within their families and communities (Ministry of Māori Development, [MOMD], 2015). Whanau Ora's approach emphasises empowering families to take control of their health and well-being and make informed choices with support, guidance, and resources. (MOMD, 2015). Even though Whanau is the central point of Māori culture, sometimes families find it challenging to assign a

pivotal person to exchange information, actively participate in decision-making, explain the procedures or treatment, and act as an advocate (Graham & Masters-Awatere, (2020). This is often due to their lack of time, skills and work or childcare commitments.

Graham and Masters-Awatere, (2020) recognise that when family members actively participate and coordinate care for their sick person, the positive health outcome is high. Masters- Awatere and Graham (2019) report that Māori patients usually receive low-quality care in hospitals, which they consider a norm. However, initiatives like Whanau Ora facilitate meaningful engagement and collaboration with healthcare providers and families. Graham and Masters-Awatere, (2020) acknowledge that Māori patients concur with the support they receive from Māori health providers as they feel culturally safe. Māori health workers act as health advisors and navigators who provide education and explain treatment and medications. Health navigation highlights the potential for improved access to services, health literacy and advocacy, and increased engagement in preventative diseases, ultimately improving health outcomes and satisfaction (MOMD),2015. Māori patients talk highly about the holistic and culturally safe care they receive from Māori health workers (Graham & Masters-Awatere, 2020).

Summary

A comprehensive examination of the selected literature was conducted to delve into the impact and influence of culture when delivering FCC in New Zealand. The review's primary focus was on Māori culture, cultural values, cultural safety, and holistic care. A rigorous review of this literature provided an understanding of how culture plays a pivotal role in delivering FCC. Few of the literature mainly examined healthcare practitioners, especially nurses' perceptions and how they comprehend the concept of FCC. A thematic descriptive analysis was used to identify major findings.

This review yielded three overarching themes 1) Respect and Dignity, 2) Participation, Communication and information sharing and 3) Collaboration. Also, under each main theme, sub-themes were derived. The review explicitly recognised the value of family and culture in a child's life. Cultural safety and holistic well-being hold paramount significance in the Māori worldview. Building trusting relationships, providing emotional support, and sharing knowledge and information, effective communication crucial elements for the successful delivery of FCC. These key elements strengthen the connection between healthcare practitioners, families, and children. Promoting collaborative efforts between healthcare practitioners, healthcare navigators, Multi-Disciplinary Team(MDT) services, patients, and families to coordinate care and decision-making will reduce health inequity and improve health outcomes. When developing a FCC charter, incorporating the above cultural considerations can ensure that our KFCH

practices align with the cultural needs of the community we serve.

Chapter 4. Findings Environmental Audit and Questionnaire development

This chapter includes the second phase of this project, which provides the results from the service evaluation and development of the Family Centred Care staff questionnaire. A service evaluation was undertaken using a modified patient and family-centred care tool (<https://www.ipfcc.org/>), which relates to the four core principles of family-centred care. This evaluation shows how KFCH currently incorporates the key principles of FCC. The second part of this phase will describe the steps taken towards the development of an FCC care questionnaire, including the exploration of the existing FCC questionnaires, the identification of key stakeholders, communication with the quality improvement team at KFCH and the identification of steps for the ethical approval to undertake a survey of staff.

4.1 Introduction

As previously described, FCC is based on a partnership model where healthcare practitioners work with families and patients to identify individual patient and family needs and deliver effective care accordingly (Feeg et al., 2018). Therefore, caregivers and the patient are an integral part of this model and must be considered and supported in all phases of service delivery. Healthcare organisations must also provide a supportive physical environment to meet the patient and family's needs (Kokorelias et al., 2019). Consistency of staff, interprofessional coordination and organisational support are key factors that support the functioning and actualisation of FCC within an organisation. On the other hand, indistinct roles, well-established or habitual professional practices, and a lack of policies and guidelines will deter the implementation of family-centred care (Coyne et al., 2018).

4.2 - Part 1. Service Evaluation.

Family-centred care is embedded in KFCH's philosophy, and the vision and values recognise the importance of family-centred care. KidzFirst bases most of its principles of care on national documents that support optimal outcomes for children and young people. The Child and Youth Wellbeing Strategy (2019) is a core document that informs the values of KFCH and is essential in that it considers the impacts of social, economic, and environmental factors on the community in Counties Manukau carefully. As part of this project, a service evaluation was performed using an assessment tool modified by the Institute for Patient and Family-centred Care (<https://www.ipfcc.org/>). This evaluation

will inform how well a service implements family-centred care principles within the practice and will identify where improvements need to be made (Kokorelias et al., 2019).

Table 5. Environment Assessment tool

Environment audit question	Findings
<p>Leadership in the Organization</p> <p>Does Kidz First Children's Hospital's vision, shared values and philosophy of care statement replicate principles of family-centred care and promote partnership with children and families?</p>	<p>Shared vision specifies the inclusion of family / Whānau.</p> <p>Shared values highlight the partnership.</p> <p>Principles of provision of care guidelines incorporate family-centred care. But not in detail.</p> <p>No guidelines are available for reference.</p>
<p>Does Kidz First Children's Hospital define quality health care? If so, does it include how children and families will experience care?</p>	<p>Quality care framework is currently out-dated, and a new version is under process.</p>
<p>Do the Kidz First Children's Hospital leaders exemplify family-centred care in their words and actions?</p>	<p>Yes, the leaders reinforce the importance of family-centred care in meetings and incorporate the FCC principle when developing policies and guidelines.</p>
<p>Patient and Family Advisors</p> <p>Does Kidz First Children's Hospital have a family advisory council?</p>	<p>Currently needs to be established in the process of developing one.</p>

<p>Do Family advisors and patients serve on committees or workgroups involved with:</p> <ul style="list-style-type: none"> ➤ Culturally and linguistically appropriate services and materials? ➤ Discharge and transition planning ➤ Education for health professionals and allied health ➤ Facility designs ➤ Developing materials for patient education ➤ Patient safety ➤ Peer-led education and support. ➤ Quality improvement ➤ Policy and procedure development ➤ Research initiatives 	<p>The patient experience group is involved in developing information pamphlets.</p> <p>A Youth Advisory Group are involved in improving adolescent transitioning to adult services alongside tertiary partners.</p> <p>Burns Support Group is actively involved in initiatives in the National Burns Centre.</p> <p>Patient Experience Group supporting the development of a Paediatric Consumer Experience group.</p>
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<p>Environment and design</p> <p>Does the design of Kidz First Children’s Hospital:</p> <ul style="list-style-type: none"> ➤ Create positive and welcoming impressions throughout for patients and families ➤ Display messages that make children and families feel like essential healthcare team members. ➤ Reflect on the diversity of the child and families served. ➤ Provide privacy and comfort ➤ Support the presence and participation of families <p>Support collaboration of MDT</p>	<p>The design of the Main entrance of Kidz First Children’s Hospital is welcoming. However, there is room for improvement, for example, refurbishing and repainting. Decals with more NZ cultural views. Healing Garden.</p> <p>Children’s right and code of rights is displayed.</p> <p>A co-designing model is in progress.</p> <p>Quiet rooms in each pod, Curtains in each room, toilet and bathroom facilities available, comfortable child and caregivers facility noticed. It lacked comfort for breastfeeding mothers, for example, reclining chairs. Play therapist team.</p> <p>Visiting policy that supports the participation of families and kitchen facilities.</p> <p>The patient status board represents the MDT presence in the care. MDT meetings for complex patient care.</p>
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<p>Child and Families Participation in Care and Decision-Making</p> <ul style="list-style-type: none"> ➤ Does Kidz First Children’s hospital policy, guidelines, and staff practice consistent with the view that families are allies for the safety and well-being of the child? ➤ Does the family/caregiver identify and participate in decision-making and care planning? ➤ Are cultural and spiritual beliefs respected and incorporated into care plans and decision-making processes? ➤ Are the child and his/her family encouraged to present and participate in the handover process? ➤ Do the child and his/her family members allow to attend doctors’ rounds? ➤ Do the child and his/her family encourage to identify their learning needs as part of the discharge plan? 	<p>Yes. Negotiation of care on initial admission and updating care plan daily.</p> <p>Updating patient status board with caregivers' names.</p> <p>Policies and guidelines that indicate importance of the family's presence during the procedure. However, not extended families participation.</p> <p>It is documented in daily nursing care plans and in-patient status boards—consent process for the procedure.</p> <p>Currently, there is no evidence of this in the daily care plan. However, this has been identified in recent certification, and we will add a session while updating e-documents. There is a specification about culture in the patient status board—also the introduction of the implicit bias project.</p> <p>During the visual handover, the outgoing nurse will introduce the child and caregiver to the incoming nurse. Participation is noticed if the child and family have any unique needs. Currently, we are working on our handover process.</p> <p>Yes. Visiting policy that supports this.</p> <p>Yes. This was identified during the hospitalisation and documented in the discharge care plan.</p> <p>Patient status board.</p>
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Patient and Family Access to

Information and Education

Are there systems available to ensure that children and families:

- Have access to complete, unbiased, and valuable information?
- Understand the purpose of taking each medication.
- Understand the responsibility of managing their child's health needs.
- They can receive education and information in their primary language at their appropriate understanding level

Do the child and family have access to their discharge summary?

Does the child and family have access to their clinical records?

Do healthcare providers have easy access to patients' medical records?

Does the documentation system support record patients and families?

Priority concern for hospitalisation

Observations

Goals.

Preferences

Family meetings and discharge family meetings with extended families for information sharing and plan of care.

Doctors, nurses, and pharmacists explain them before prescribing and administering them—also, medication reconciliation meetings before discharge.

This will be identified throughout the hospitalisation period. Nurses, doctors, and wider MDT discuss and provide the necessary support to the family.

Use of Interpreting service

- Lack of cultural support people identified.
- Lack of information pamphlets on multiple languages noted.

Yes, a discharge copy will be given to the child's family and explained, which will be documented in the discharge care plan.

Yes, there is a process to follow for obtaining clinical records.

Yes, easy access via the clinical portal and centric.

Currently, Priority concern is documented in the hard copy of clinical notes. However, e - document is under process.

Currently on hard copy. e- vital in the process

We are documenting it only in the inpatient status board. Needs improvement in this.

Preferences are not recorded currently

Education for Leaders and Staff	
Do orientation and education programs provide for staff include family-centred care, collaboration with patients, families, and wider MDT?	The current orientation and education programme need to be revised.
Do orientation and education programmes provide a better understanding of culturally responsive practice?	Current education and orientation need to be improved.
Are patients and families involved in the faculty of education and training for staff?	Not currently.

4.2 a Leadership in the organisation.

McCarthy and Guerin (2021, p. 2) highlight that "Family centred care is conceptualised as a philosophical approach to paediatric care characterised by key principles and practices, rather than the delivery of formal interventions/treatments". During this evaluation, it was identified that our organisational vision, values, and philosophy are underpinned by principles of FCC and promote partnership with children and families

4.2 b Shared vision.

KFCH's shared vision highlights the significance of whānau involvement in childcare. "Kidz First will promote children's and young people's well-being in the context of their family/whanau, culture and wider environment" (*Kidz First About Us*). We will pursue this vision through the following:

- The provision and support of effective and innovative child and youth health services.
- Education, training, research and advocacy of child and youth health.
- Integration and coordination with other child and youth service providers (*Kidz First About Us*).

4.2 c Shared Values

- We will recognise that the family/whānau is constant in the child's/young person's life while services and health professionals change.
- We will deliver services in partnership with the family/whānau.
- We will provide services that recognise and respond to the developmental, cultural, social, and spiritual needs of children, young people and their families/whānau.
- We will actively promote the well-being and care of children/young people in their homes and the wider environment.
- We will ensure that children / young people are cared for by health professionals who embrace family / whānau-focused care.
- We will support and promote the development of child and youth health expertise for all staff working within the services. We will provide dedicated facilities for children, young people, and their families / whānau.
- We will embrace the "Code of Health and Disability Services Consumers' Rights" and "The Right of a Child when Receiving Health Care". (*Kidz First About Us*).

This vision and values are available on the Kidz First website and are briefly mentioned in our principles of provision of care. However, during the environmental audit it was noted that our vision and value are not displayed anywhere in KFCH services available to the public. Based on the search in Te Whatu Ora counties Manukau database (*CMDHB Documentation Directory*), no family centred care guideline or policy was available specifically for children and young people. This is problematic given that it is recognised that FCC policies are vital documents that validate and support families' participation and understanding in their family member's care (Kafulafula et al., 2019; Kokorelias et al., 2019). The leadership team is currently working on improving family-centred care practice, and when developing policies and guidelines, preferences are given to integrate FCC principles. Kuo et al. (2012) assert that healthcare organisations must recognise the importance of family-centred care principles and include it in care delivery and when developing practice guidelines. Kidz First Children's Hospital's current quality care framework needs to be updated, and a newer version is already drafted and awaiting approval from authorities.

4.2 d Patient and Family Advisors.

The audit revealed that no family advisory council currently exists, but through conversations with colleagues and managers it was noted that a paediatric consumer group is being explored to capture both child and patient voices. KFCH does involve patients and families (patient Experience Action Group) in developing information pamphlets to ensure the comprehensibility. A good example of this is the youth advisory group, which includes adolescent patients and families and ensures a smooth transition of adolescent to adult services. There are multiple advantages when patient and family advisors are engaged in quality improvement projects. This includes better health outcomes for patients, a reduction in medical errors and adverse events, and both consumer and health professionals increased satisfaction (Ramazani et al., 2020). Currently, KFCH is supported by the Patient Experience Action Group in Middlemore Hospital to develop a paediatric consumer experience group, and this is an important area for further development

4.2 e Environment and Design.

Wilson et al. (2021) describe how Māori families feel hospital environments are not healing environments but rather a space that is tailored for European culture. Also, Māori families feels that Māori culture and spiritual practices are disdained in hospitals KFCH's entrance is relatively welcoming, with a traditional Māori carving of Mother and Child and Māori design artwork on the right-side wall (refer to Figure 2). There is no other visual evidence that support Māori culture and tradition either in the ward area or at the main entrance. There is room for improvement, and a plan is in progress to create a more child-friendly and culturally appropriate environment with paintings and decals in KFCH. KFCH has a healing garden that patients and families can access and feel closer to nature even when stressed and alienated in the hospital. The specialist team is working closely with Middlemore Foundation to upgrade the healing garden to be more culturally appropriate. These planned improvements will help to go some way towards including a Māori worldview of holistic care, which is not only physical or psychological, but relational. It is evident that Māori children and whanau will feel safe and valued when they believe the environment is one that provides holistic care (Wilson et al., 2021).

Child and family-friendly hospital environments are known to enhance family-centred care delivery (Coyne et al., 2011). At present, KFCH environment does not appear child friendly on arrival to the ward, and this has been acknowledged by the leadership team and commented on by patients and family (refer to Figure 3, 4). Purposeful collaboration is underway with Mana Whenua to ensure that any initiative is co-designed and informed with equity at the core and guided by obligations to Te Tiriti o Waitangi (Pae Ora

Act,2022). During the environmental audit it was noted that children's rights and code of rights are displayed and available in card forms for patients and families if needed. These codes of right are displayed in English, Māori, and sign language and was a positive finding during the audit (refer to Figures 5, 6). Other positive and important aspects of FCC that were evident during the audit were related to the fact that KFCH provides comfortable accommodation for the child and a parent or caregiver during hospitalisation. Both parents can stay if the child is critically unwell or the situation manifests (Figure 8). Caregivers are allowed free parking and the hospital supply meals daily; the kitchen facility is also available for coffee and tea (refer to Figure 7). The toilet and shower facilities are available in each single room and shared in double rooms and the hospital provides toiletries and personal care items for the child and the caregiver. Family rooms are available at the end of each wing of the ward. This space is a private space where families want to have private conversations. These findings were reassuring and indicated that we are getting some aspects of a FCC approach right for whanau. KFCH's play specialists are vital in keeping the child and family comfortable. They incorporate FCC principles in their practice. With all its facilities, the playroom is a comfortable and much-loved space for children (refer to Figure 10). They offer support for parents without family support and relieve parents for a break. When siblings visit the patient, they make them space to play together (non-isolation patients). During procedures, they support the child and family to make them feel comfortable, and they prep them prior to procedures to relieve anxiety.

Kidzfirst has an open visiting policy, and parents can visit anytime, and extended family members are allowed between 1400 hrs to 2000hrs. These restricted times for extended family are very likely problematic for Māori families who prefer extended family members to be as included as the primary caregivers in terms of access to the hospital. Parents or a caregiver is allowed to stay during ward rounds, and they are enabled to provide feedback about their child's care to the team. Currently, we lack comfortable reclining chairs for breastfeeding parents. Also, parents often find it uncomfortable when an extra caregiver is staying. Often children have many members of the multi-disciplinary team (MDT) involved in their care. The patient status board in each room displays the MDT's name involved in care and these aids family members in identifying team members. MDT meetings are held every Tuesday to discuss the complex patients. Parents are not included in this MDT as the focus is on clinical planning, however this is an area worth exploring further, as parent involvement may provide important insights and input into this planning and would demonstrate a more family inclusive approach.

Below you will see several images captured from the environmental audit. These pictures demonstrate some of the positive findings and areas where improvements could be made as described above.

Figure 2. Picture of carving and Māori artwork at the entrance of Kidz First



Figure 3. Kidz First reception area



Figure 4. Kidz First ward



Figure 5. Display of Code of rights



Figure 6. Display of child rights



Figure 7. Kitchen



Figure 8. Patient room



Figure 9. Family room



Figure 10. Play room



4.2 f Child and Families Participation in Care and Decision-Making.

Kidz First Children Hospital supports parents and caregivers to always be present with their children. Parents or caregivers can stay with the child during procedures like IV leuc insertions, naso gastric tube insertion, lumbar puncture and even during resuscitation. All the procedural guidelines explain the procedure to the child and family. Verbal consent and written consent forms are signed by parents prior to the procedures according to the policy and the play specialist team supports the child and family along with the nurses and doctors during these procedures. Our current workforce will need more education about the importance of providing safe spaces and comfort for patients during procedures. The interpreting team is available when patients and families do not speak English or need clarification or explanation. Also, they are referred to social workers if they require support. Māori patients and families are referred to the Māori health team.

After admission, parents or caregivers can stay, and nurses introduce them to the ward surroundings. According to the policy, within 24 hours of admission, a care plan must be drawn up in negotiation with the family and age-appropriate child. Care plans for long-term and medically complex patients guide their daily care, especially when they are transferred from another facility and have already developed a routine. Nevertheless, this is often incomplete due to the ward's busyness and staff shortage, and nurses concentrate mainly on completing tasks. In the real world, nurses and doctors are

supposed to explain and negotiate care plans and recheck with them if they have any questions or further clarification. Also, the care plan needs to be updated every shift. Further education for the current workforce and resolving the staffing issue will be necessary to manage ongoing issues with maintaining these standards of practice.

During the audit one of the most disappointing findings was that the documents reviewed showed no evidence of respecting culture and spiritual beliefs. This was also identified in the recent certification. The admission document has now been edited to include culture and spiritual needs as part of the admission process to capture this information, and the SBARR template in the e-notes will reflect this as an ongoing measure to capture this information throughout the patient's journey in the hospital. The patient status board (refer to Figure 10) has space to capture the culture; however, only some families are willing to respond to this question. This may need further surveys to determine why this question is not always answered. In Kidz First, the handover process includes both visuals and verbal handover. During visual handover, outgoing nurses introduce the incoming nurse to the child and caregiver and perform all the checks, including PAT assessment, fluids, feeds, IV line, and bedside emergency equipment. Parents/caregivers and children are encouraged to stay during visual handovers. Verbal handover, detailed information about the patient's condition management and plan happens in the nurse's handover room, not in front of the patient or family. Parent participation happens very seldom during the handover process. KFCH wards need to do better with discharge planning education, which was identified in the certification. Corrective actions must be taken to enhance collaborative discharge planning and education.

Figure 11. Patient status board

The image shows a 'Patient Status Board' with the following sections and content:

- Header:** 'Patient Status Board' with a room number field.
- Personal Info:** My preferred name, My nurse, My play specialist, My support person for today is, My culture, Language spoken, Interpreter (N, Y).
- Today's Info:** Today's date (dd/mm), My comfort things are (Family, Device/Toy, Sensory Needs), Other.
- Needs & Goals:** My plan/goal for today is, My question for today is, I need help with (Toileting, Mobilising, Hygiene Care), My specific needs are.
- Feeding & Drinking:** Can I eat today (Feeding Parent/caregiver ONLY, Nurse OK), Feeding plan (N, Y), Can I drink today (Independent, Assisted).
- Medical Visits:** I am being seen by (Occupational Therapist, Physiotherapist, Social Worker, PCLT, Pharmacist, Speech Language Therapist, Dietitian).
- Pain Scale:** Pain Scale (1-5), Pain Goal.
- Home Discharge:** When I get to go home (< 3 days, 3-7 days, > 7 days), What I need to go home (Education, Medications, Referrals & Appointment, Supplies/equipment, Feedback form).
- Footer:** Last updated: dd/mm hh:mm, Te Whatu Ora Health New Zealand.

4.2g Patient and Family Access to Information and Education.

Parents/caregivers and patients will be fully informed about their medical condition, and they are encouraged to ask questions during ward rounds. Family hui will be organised for more complex patients, and extended families or friends can attend. Cultural and spiritual needs are not given the expected preferences during this hui. For example, this family hui is not often started with a karakia and cultural needs or spiritual needs are not discussed in detail. Rather this hui is mainly to explain only the medical condition of the patient. Further education and training are required for the staff, doctors, and allied health professionals. However, I firmly believe the implicit bias project (moving toward anti-racist discourse and practice to achieve health equity) initiated in KFCH will shed light on this. In the past, information pamphlets were not reachable for the patients and families, and now these are stocked where parents and families have easy access. However, the current stock is mainly in English, and further work needs to be initiated to stock up pamphlets in different languages (refer to Figure 12).

Pharmacists, doctors, and nurses educate patients and families about the prescribed medications, and medication reconciliation meetings will be conducted before discharge. Nurses, doctors, and a more comprehensive MDT conduct professional meetings before

discharge family meetings to discuss the support, prepare and empower the family to participate in the child's care at home. Interpreting services will be included accordingly. previously we had a cultural support person available in the ward. Over time this role has been taken away, and therefore, accessing cultural support is not easy now. This service access must be improved to initiate cultural safety when providing family-centred care. Healthcare providers have easy access to medical records, especially after moving on to e-documents. KFCH services will be moving to e-vitals soon, which will be more beneficial.

For families who want to access clinical records, an application form must be submitted to clinical records, and clinical records will release the records in due time. We have a problem list in hard copy, usually filled by the medical team. Recently, this is not being filled out as we have partially moved over to electronic documents. Patients' preferences and goals could be documented better but are sometimes mentioned in clinical notes and nurses' notes.

Figure 12. Information Pamphlet for patients



4.2 h Education for Leaders and Staff

There is a clear deficiency in comprehending how to incorporate FCC principles in clinical

practice. Currently, the audit revealed that there is no policy or guideline available for reference. The new graduate orientation programme mentions FCC but does not give further elaborations or instruction about the concept. Two education training programs offered by the hospital that focused on engaging effectively with Māori and Pacific cultures were available as study days in the past, however these courses are now unavailable.

Kidzfirst does have some mandatory training which includes 'Building Cultural Capability for Counties' however the numbers of staff attending this mandatory training is insufficient to really say that we provide culturally safe care (Refer to Table 4). This is evident from the feedback form filled out by patients and for example families. Much work is needed to improve cultural safety in KFCH. For example, recently, we received feedback from a family stating that *'overseas nurses are good at clinical skills but need to interact better with the child and the family, pronounce the child's name correctly, and explain the procedures to families'*. Involving the patient and family advisory board to facilitate cultural safety training will significantly improve cultural safety and patient health outcomes and do some work towards achieving better health equity.

Table 4. Mandatory training for new employees of Te Whatu Ora Counties Manukau (CMDHB, 2022)

<i>Mandatory for All CMDHB Staff</i>
KoAwhatea: Basic life support Yearly online biannually face to face
KoAwhatea: Nga Paerewa Te Tiriti o Waitangi
KoAwhatea: Building Cultural Capability for Counties
KoAwhatea: Disability Responsiveness CMH
KoAwhatea: Fire Safety
KoAwhatea: Health & Safety Induction
KoAwhatea: Health literacy
KoAwhatea: Infection Control
KoAwhatea: Privacy of Personal & Health Information
KoAwhatea: Safety-first (Incident and Feedback Reporting)
KoAwhatea: Understanding bias in healthcare
KoAwhatea: Code of Conduct
KoAwhatea: Delegation and Direction 101-Nursing

4.3. Part 2 - Development of an electronic questionnaire for future implementation.

For phase two-part two, the initial plan was to develop a robust questionnaire after consulting with the stakeholders, including Māori and Pacific advisors. However, due to

time constraints, only the first initial steps were covered and are described next.

I had initially planned to explore what FCC questionnaires already currently exist in the literature. As mentioned in the previous chapters, family-centred care is the prominent model of care in paediatric hospitals globally; however, despite this universal acceptance, there are multiple barriers to successful implementation, including both family and healthcare practitioner's stress, organisational limitations and lack of policies, challenging demands, power imbalances, staff's perceptions and understanding of FCC (Coyne et al., 2013; Feeg et al., 2018; Foster et al., 2016; Rosenthal et al., 2022; Family Voices, 2013). Because of these noted challenges, researchers have created and conducted family and staff surveys to explore the above reasons and to identify other key issues and make suggestions to improve practice (Arslan et al., 2018; Coyne et al., 2013; Curley et al., 2013; Skene et al., 2019). I found several existing FCC questionnaires through a general search of google scholar and the CINAHL database. However, many of these (rightfully) focused on children and families rather than health professionals. I decided to look at three tools related to healthcare professionals' perceptions and practices of FCC.

4.3a Family Centred Care Assessment Tools.

The **FCC self-assessment tool** was originally designed by an organisation called Family Voices (Family Voices, 2013). The tool was developed through in-person meetings, conference calls, and interviews led by expert family leaders and healthcare providers (Family Voices, 2013). The questions were revised and tested through a validation process that included research with multiple family focus groups and a national survey of family respondents. The resulting 24 quality measurement questions were found to be psychometrically sound, with documented high reliability and evidence of empirical validity (Wells et al., 2015). It was originally designed to be used in outpatient care settings; however, some elements could be helpful and adapted to our inpatient setting at KFCH.

In addition, a detailed user guide on the Family Voices website provides clear instructions on how organisations can use the tool and essential preparatory work and tasks to be completed before undertaking a staff survey (<https://familyvoices.org/fcca/>). The tool is divided into three major sections: 1) Family/Provider Partnership, 2) Care Setting Practices and Policies and 3) Community Systems of Services and Supports. Within each of these major sections, some subtopics address many elements of FCC. One of the potential disadvantages of adapting this tool for the KFCH setting is that it is an acute care setting with families coming and going. Therefore, it may be more challenging for

staff to respond to some questions. However, it would still offer an important opportunity for staff to reflect on their own practice.

Family Centred Care Questionnaire-Revised (FCCQ-R). The FCCQ-R was originally developed by Bruce and Ritchie (1997) and originally had 55 items distributed. Over nine subscales represented each of the eight elements of family-centred care. The tool has been revised over the years and is now a 45-item questionnaire that measures health professionals' perceptions of the practice and importance of 9 core dimensions of FCC (Franck et al., 2021). Items are rated from 1 "strongly disagree" to 5 "strongly agree" with respect to respondents' perceptions of their current clinical practice (Current Practice scale) and how necessary they consider the item to effectively practice FCC (Necessary Practice scale) (Franck et al., 2021). Child and youth researchers have widely used this tool, and it is generally considered a useful, valid, and reliable instrument for assessing nurses' attitudes towards the importance of involving families in their clinical practice (Alfarao et al., 2019). Coyne et al. (2013) surveyed paediatric hospital nurses in Ireland using the FCCQ-R to identify their practices and perceptions of family-centred care. They found differences in nurses' practices and perceptions of FCC. Nurses generally consider emotional and financial support and recognise family individuality as essential for family-centred care. In nurses' perception, the design of the health care system was not an element for delivering FCC. This study is a useful one to think about in the context of developing a survey for KFCH, especially given the current staff shortages and changes to the structure of our hospital. In the Coyne et al. (2013) study, the results point out that nurses need more control over staffing issues, weekend services and the hospital's physical design. To conclude, Coyne et al., (2013) agree that nurses acknowledge the importance of FCC but can only sometimes implement it due to limited support from organisations, lack of resources and hospital design. This questionnaire, although lengthy, holds the most promise to be used as a potential tool for questioning staff at KFCH about perceptions of FCC.

Family Centered Care Questionnaire (Skene et al., 2019). The researchers developed this tool specifically for their study, which still needs validation. The questionnaire comprised items relating to FCC modified from a survey developed by Warren (2015). They also added and adapted other questions focusing on perceived competence from the maternal parenting self-efficacy questionnaire (Barnes & Adamson-Macleod, 2007). This questionnaire has 37 questions divided into five sections that explore perceptions of information sharing with parents, family support, parental participation in care, nursery values, and nurses' self-assessment of their competence in FCC. Each item was scored on a 5-point Likert scale from strongly agree (5) to strongly disagree (1). This survey was

designed for a Neonatal Intensive Care environment; however, it may be helpful to consider adapting for our KFCH setting, especially given its potential ability to help develop a charter for FCC. For example, Skene et al. (2019) surveyed nurses and parents to understand parental involvement in caring for NICU babies. Based on the findings from the survey, they developed a framework for establishing family-centred care. Findings from the initial survey recognised the necessity of education on FCC for nursing staff and more active involvement from parents. A post-survey on nurses showed much-improved family-centred care perceptions, mainly on information sharing, providing support for parents and aiding parental participation (Skene et al., 2019). In this review, most family-centred care survey questionnaires are developed to measure families' care experiences or understand nurses' perceptions of family-centred care. However, developing a family-centred care charter survey must include other healthcare professionals to understand their perceptions as they also participate in implementing FCC. The plan for this project would be to develop a questionnaire that could be sent to all healthcare professionals that care for children at KFCH. Hence, it is crucial to consider who will be the key stakeholders for developing and taking part in an FCC survey or questionnaire.

4.3 b Identify key stakeholders and consult with the Quality and Risk Manager.

In many ways, the main stakeholders for this project have already been identified during the evolution of this project. Through conversations with doctors, nurses, play specialists, pharmacists, physiotherapists, dietitians, Speech and Language Therapist, Māori and Pacific cultural advisors, Quality and Risk Manager, Clinical Nurse Director, and Service Manager at the leadership level, there is a strong commitment within our team to improve our family centred care practice and to assess it using a survey or questionnaire. When eventually developing or modifying a survey, I will consult with all of these key stakeholders throughout the development process.

4.3 c Clarify goals and identify practical problems.

The main goal of the proposed survey is to explore health professionals' perceptions, principles, and practices relating to FCC to inform the establishment of family centred care charter for KFCH. It was essential to consider and brainstorm some of the practical problems that may arise.

1. Unavailability of staff due to the busyness of the ward. Therefore, consideration should be given to implementing the survey during less busy periods for example in the summer.

2. Participants may not want to sit through a long questionnaire so consideration should be given, and research done on suitable and acceptable lengths of questionnaires.
3. Some participants may need support if the online survey platform is too complicated, especially for those staff where English is a second language.
4. Considerations will need to be given to ensure that participant have access to devices to complete the survey.
5. It may be important to consider the way in which a survey would be distributed. Staff often do not access their emails, and this is a potential problem that will need to be considered.
6. Lastly one of the most important considerations will be to allow time to complete ethics approval.

4.3 d Explore the approvals required and the process for administering a questionnaire to staff at KFCH.

As this survey includes Te Whatu Ora Counties employees, ethics approval must be obtained to ensure the survey's compliance with appropriate ethical standards. Also, locality approval must be obtained from Te Whatu Ora Counties - and this survey application must be submitted to the Kidz First Research Committee for endorsement. In addition, a process of approval must occur with the Maaori research advisory group. This is a long process, so allowing extra weeks on the timeline will be necessary. After obtaining the above approvals, it will be essential to discuss with Clinical Nurse Director, the Service Manager, charge nurse managers, and respective managers of multidisciplinary teams for approval. An introduction about the intended study will be helpful for the staff, and this can be done during ward meetings. Questionnaires can be sent out to the participant's email address. Also, printed versions can be distributed among staff or leave it in the ward for easy access.

4.3 e Explore various platforms such as Redcap and Survey Monkey.

Several platforms in existence could be used to undertake the staff survey. The two that I looked at were REDCap and Survey Monkey. "Research Electronic Data Capture (REDCap) is a secure web application designed by Vanderbilt University to build and manage online surveys and databases in the research setting for universities."(Harvey, 2018 p 1.). REDCap is a customisable data collection tool with a comprehensible data entry port. Also, its advanced tracking system enables recording multiple users' actions. Therefore, a complete audit trail can be created without accidentally or intentionally changing data. Also, hard copies can be scanned and filed on the database. Survey

Monkey is another commercial online software data gathering tool to format and manage the survey (Hutchinson et al., 2008). However, Te Whatu Ora Counties use REDCap software for data management, so this will likely be the platform of choice for the FCC survey once developed.

Summary

This chapter presents the service evaluation and initial steps for developing a questionnaire for future research to understand healthcare practitioners' perception of FCC. Findings from service evaluation support the significance of developing policy, guidelines, training, and cultural awareness before developing a charter.

Chapter 5 Discussion

The overall aim of this project was to lead the way to develop an action plan and make recommendations towards forming a Family Centered Care charter for KFCH. This discussion will summarise the overall themes generated from the literature review, service evaluation, the significance of the staff survey and initial steps to develop a survey. In addition, this chapter will include the limitations of this project, next steps, and a conclusion.

This project involved two phases: a literature review and service evaluation of KFCH, including a preliminary workup towards developing a family-centred care questionnaire for staff. Through undertaking these phases, I have developed key recommendations that need to be considered when developing the FCC charter at KFCH that fall under 3-4 categories.

5.1 Family and Culture, Holistic health and well-being, Cultural Safety

Findings from this analysis show that family and culture play a pivotal role in the health outcome of a hospitalised child. The strong connection between children and family and their centrality in New Zealand culture has been identified by multiple researchers (Adcock et al., 2021; Crawford et al., 2017; Foster & Whitehead, 2017). Māori consider inter-generational well-being as a collective responsibility, not as an individual responsibility, where Māori Whānau uses their ancestor's knowledge and spiritual practice for the well-being of their child and Whanau (Adcock et al., 2021; Wilson et al., 2021). There is strong evidence from the literature that active involvement of the family and meeting their cultural and spiritual needs will enhance better health outcomes and satisfaction (Adcock et al., 2021; Graham & Masters-Awatere, 2020; Tipa et al., 2015; Wilson et al., 2021). Unfortunately, the service evaluation shows that although KFCH's model of care delivery deems to be family-centred, meeting the child's and family's cultural and spiritual needs is not fully reflected in our care and documentation. In addition, the absence of a family advisory council points to a significant deficit in practice. This concern has been identified in recent external certification, and there are plans in place to address this issue. However, the organisation is still committed to the shared value promise of actively promoting the well-being and care of children in their homes and the wider environment.

In the literature review, Adcock et al. (2021) described how parents often feel they are hemmed in by the cultural boundaries of the hospital even though the hospital philosophy claims to be underpinned by FCC. The FCC elements within KFCH attempt to address these cultural boundaries. KFCH visiting policy allows both parents or a caregiver to stay during the daytime but limits to one parent or caregiver during the night. While this policy may suit some whanau, for other whanau, this may feel culturally restrictive. However, notably this visiting policy can be modified on an individual basis. For instance, autism spectrum disorder (ASD) children need a higher level of attention in the hospital as they are susceptible to getting distressed and agitated (Thom et al., 2020). They may need more than one caregiver to meet their needs effectively. Certain families may have other children with similar conditions or some other special care needs for which they get help from extended families. Recognizing and understanding these families' social needs is essential for healthcare practitioners when delivering FCC. Unfortunately, there are instances where nurses deny this special permission for various reasons such as lack of recognition of extended families in a child's care, lack of resources, time and understanding of FCC principles or stereotypical assumptions of staff.

Evidence from literature suggests that hospital policies that prevent the participation of extended families in their child's care are considered culturally unsafe (Adcock et al., 2021). When nurses inherit such implicit culture of the unit, it prevents them from acting as a broker for patients (Adcock et al., 2021; Crawford et al., 2017). Altering the visiting policy allowing family members more time to participate in their child's care will enhance interaction with healthcare practitioners and family, and ultimately caregivers are experts in their child's care (Kokorelias et al., 2019). Reports of such implicit bias within the environment at KFCH are evident in the comments from patient experience feedback and report. For example, in many cases, grandparents become caregivers for their grandchildren, and they acquire valuable knowledge and skills to care for a complex child. However, when they are in KFCH as inpatient, the policy does not permit them to perform suctioning or give special feeds, despite the fact they may do this at home. The system does not allow for more than one set of 'main caregivers'. This implicit bias inherent in the system does not recognise extended family members and the role that they play (Adcock et al., 2021). This culture can create negative experiences for the family and may lead them to disengage with the healthcare team. This is an important issue that must be addressed in terms of our policy and as key element of any quality initiative. The evidence from the literature review shows the significance of extended families' participation in a child's care improves health outcomes, parental satisfaction, and the emotional well-being of both the child and the parents. Beyond bedside care, Ramazani et al. (2020) strongly argues that involving patient and family in policymaking and quality

improvement projects can improve health outcomes, reduce adverse events, medication errors and improve both patient and professional's satisfaction.

Families feel comfortable and positive when healthcare practitioners are empathetic and practice culturally safe care. Healthcare providers must understand that receiving culturally safe care is a fundamental right for every patient and upskilling the staff for this is an organisational requirement. Introducing an FCC model in a culturally safe way will enhance the health outcome of patients and family satisfaction (Adcock et al., 2017; Curtis et al., 2019; Foster & Whitehead, 2017).

Evaluation of the service reveals that our current workforce does not represent our ethnic demographic. Evidence from literature shows that significant representation of the Māori workforce who understand the culture and needs of individual Māori patients will pave the way to achieving health equity. Nonetheless, this will take a long time and effort, and the non-indigenous workforce will continue caring for Māori patients and whanau (Wilson et al., 2021). To provide culturally safe and equitable care for indigenous patients, Wilson et al. (2021) suggests relational care, which is a person- and Whanau-centred, holistic healthcare practice that evolves through mindful reflection and deliberation. Service evaluation highlighted that most of our current workforce are new graduates and overseas-trained nurses who require intense cultural safety training to cater to and provide appropriate care for our Te Whatu Ora Counties Manukau population.

5.2 Building relationships, emotional support, communication, and information sharing.

Findings from this analysis highlighted the value of participation when delivering FCC. A trusting relationship weaved by healthcare practitioners with patients and families will enhance the family's involvement in decision- making. Manaakitanga (kindness, **generosity**)) and Aroha (**empathy and compassion**) are the two cultural values that will help the health care providers to establish a trusting relationship with Māori patients and Whanau (Wilson et al., 2021). Both parents and healthcare practitioners expect parental participation in caring for their sick children. However, this expectation will be achievable only through honest and non-judgemental interactions and by creating a trusting relationship (Crawford et al., 2017; Wilson et al., 2021). Similarly, many other researchers highlight the significance of building trusting relationships through open and transparent communication, information sharing (Kokorelias et al., 2019; Kuo et al., 2012; Shields et al., 2012).

KFCH's shared value supports the findings from the literature, as the organisation is

committed to delivering services in partnership with Whānau. Service evaluation confirmed that KFCH allows parents to participate in their child's care by allowing them to stay with them all the time, including procedures and even in emergency resuscitation situations. Guidelines and policies support the participation of parents in care and decision-making. The play specialist team for example supports the child and family during procedures. According to the policy and guidelines, care plans must be prepared in negotiation with the family, however this is not evident in everyday practice in the current environment. For instance, patients with long-term conditions like rheumatic fever, severe burns, single ventricle babies, post-cardiac surgery, and bronchiectasis necessitate individual care planning and goal setting. When such patients are transferred from other facilities, disruptions to their routines can adversely affect the well-being of both child and family, potentially affecting their overall health outcome. Kokorelias et al. (2019) strongly support this in their study as they suggest developing care plans according to the individual's unique needs in a family context will improve family satisfaction and patient health outcome.

Research findings identify that establishing respectful relationships, characterised by consideration, and focused on knowing the family, is a foundation for establishing partnerships with Māori patients and families (Tipa et al., 2015). Education, staff training, and appropriate staffing levels are essential to progress in negotiating care and building this relationship. Service evaluation identified the need for policies and guidelines on FCC, and healthcare practitioners need more education and training on communication and information sharing. Multiple researchers acknowledge this in their studies. (Kokorelias, 2019; Kuo et al., 2012). Literature analysis shows that while patients are hospitalised, the healthcare provider's positive connections and interactions are fundamental to their emotions. Providing emotional support is the role of a healthcare practitioner during this challenging time for the family (Adcock et al., 2021; Crawford et al., 2017; Graham & Masters-Awatere, 2020). In KFCH, the patients will be referred to appropriate teams of Paediatric psych liaison consultants, social workers, Māori, and Pacific health teams. However, early recognition of the need for emotional support and timely referral will benefit both patient and family. The analysis identified the lack of cultural elements in information sharing and communication. Sincere, evident and respectful communication enhances the successful delivery of family-centred care and patient and family satisfaction. (Foster & Whitehead, 2017). Patients and families feel neglected and stressed when information is delivered in a pamphlet form and not explained by a healthcare practitioner. As a result, their trust in the healthcare system fades away, and they gradually disconnect from the health system.

Lack of information sharing is a flaw in health care when providing quality and safe patient care (Graham & Masters-Awatere, 2020). Service evaluation identified that our information pamphlets are mainly in English, which must be addressed urgently. Our population in South Auckland is diverse, and we need pamphlets in multiple languages. Our medical and MDT provide adequate information for patients and families without fail; however, the nursing team needs increased awareness. This is evident from my charge nurse observation and family's feedback. I acknowledge that our nursing team is very busy, and they are very task oriented. They may benefit from additional communication and information-sharing education, especially communicating and engaging effectively with Māori. Literature supports this as Māori patients and families find it challenging to provoke their healthcare practitioners by asking questions as they are too busy (Graham & Masters-Awatere, 2020). Subsequently, patients underrate their pain and cover up their symptoms and hide their concerns to avoid troubling the practitioners (Graham & Masters-Awatere, 2020). Research done by Tipa et al. (2015) shows that health professionals with family partnership model training were confident, communicated very well with families, were active listeners and good at prompting and exploring.

5.3 Social determinants of health, power imbalance, health navigation.

The literature review revealed that historical colonisation caused significant damage to the Māori population's health and wealth, which resulted in the current socioeconomic deprivation faced by Māori (Curtis et al., 2019). Inequitable access and the social determinants of health, such as poor housing, lack of education, transportation, neighbourhoods and access to health services and safe and quality health care, contributes to these poor health outcomes of Māori (Wilson et al., 2021; Masters - Awatere & Graham, 2019). Identifying socioeconomic needs, referring to appropriate services, and offering needed resources are particularly important when providing safe and quality care. Collaborating with other services and a wider multi-disciplinary team within the hospital will be time-consuming for healthcare practitioners; therefore, health practitioners sometimes avoid this responsibility (Crawford et al., 2017; Foster & Whitehead, 2017).

The service evaluation supports this notion and proves that Kidz First Children's Hospital is not consistently identifying the social determinants of health that impact our patient population. Measures must be taken to capture these influences and needs when developing care plans and discharge planning. For example, during a particular instance a single parent with multiple children was admitted and the mother was too unwell to get her prescription. Consequently, she was left without medication until a staff member recognised this and got medication at her own expense. The same family needed flu

vaccination and lacked transportation. After a lot of discussion and planning the charge nurse liaised with public health nurses and asked the nurses to go to the family's home instead. Surprisingly all these things happened on the day of discharge as there had been no discharge planning or goal setting conducted upon admission. Shields et al. (2012) identify a major element of FCC as "adopting policies and practices that provide families with emotional and financial support" (P.3). Curtis et al. (2019) argues that "healthcare professionals and healthcare organisations are the critical contributors to racial and ethnic inequities in health care " (p. 2) and these inequities are the results of biased power dynamics. Healthcare practitioners must recognise the patients' and families' needs, skills, and knowledge and acknowledge this power imbalance exists. Rather than enforcing these skills and knowledge, practitioners must empower the patient and family, improve their self-care efficiency, and take ownership of their health (Wilson et al., 2021).

Service evaluation shows that the patient and families receive education and training prior to discharge. However, identifying the educational needs early will enhance early discharge. Also, KFCH must recognise the vitality of Māori involvement in developing healthcare policies and initiatives. Māori led health initiatives will underpin the unique needs of Māori and emphasise collaboration and partnership. This will have great acceptance in Māori communities (Graham & Masters-Awatere, 2020). Healthcare navigation can be challenging for families as it requires time, energy, and skill. (Masters -Awatere & Graham, 2019). In the past, KFCH had Māori and Pacific health support workers available daily in the ward. Service evaluation showed the significance of their absence, as accessing the team and getting support is time-consuming. Understanding the limitations of patient knowledge, listening to their needs, valuing their cultural needs, and working in partnership with patients and families rather than imposing nursing knowledge will enhance health outcomes and satisfaction (Richardson et al., 2017).

Key Recommendations for The FCC Charter

In summary, the literature review and environmental audit have resulted in the following key recommendations that need to be considered when developing the FCC charter:

1. Development of the charter principles must place children, young people, and whanau at the centre of a culturally safe system. Develop a policy and guidelines for FCC.
2. Children, young people, and whanau must be allowed to provide feedback and input into delivering care. This could be through an advisory group role.
3. KFCH must commit to creating an environment where collaboration among children, young people, families/whanau, and providers occurs in policy and programme development, professional education, and care delivery.
4. Identify and support social, developmental, and cultural factors that may impact communication. Provide communication and information-sharing education for nursing staff. Re-consider programmes such as engaging effectively with Māori and Pacific cultural training.
5. Provide education and training for the healthcare practitioners on FCC and available resources and services in the community.
6. Implement mandatory cultural safety training for the entire staff—specialised cultural training for overseas nurses addressing the challenges they may encounter in the new cultural context.
7. Consider how we can recruit and retain Māori and Pacific workforce, such as well-organised culturally focused fundamentals of care training for students during clinical placements. Consider flexible shifts. Revise the work roster to improve consistency of care.
8. Flexibility in visiting hours for extended family members according to the needs of the child and family for the culturally safe delivery of FCC.
9. Assess the current process of setting goals and negotiating care and discharge plans for individual patients and families.
10. Prioritise a negotiated and Planned transfer of chronic patients between healthcare facilities which involves coordination and collaboration with doctors, nurses, wider MDT, patient, and family.
11. Ensure information pamphlets are available in multi-languages. Consider creating a working group for writing pamphlets, involving patients and family members in this group.
12. Prioritise a hospital environment that is both child friendly and culturally appropriate. Ensure cultural sensitivity in the physical environment to create a

sense of familiarity and inclusivity. More reclining chairs for breastfeeding mums for comfort. Consider building an expressed breast milk storage and preparation facility that parents can access.

13. Generating funding for obtaining medication from Haumanu pharmacy for the parents who cannot afford to pay while in the hospital.
14. Recommencing Māori and cultural support and ensuring they are easily accessible.
15. Review current visiting policy to accommodate the individual child and family's need.
16. Consider establishing a family liaison nurse role in each ward.

Limitations

It should be acknowledged that the literature review in this project was restricted to studies published from 2011 to 2022, and included studies only written in English. It is also important to note that the project was conducted, and the literature was reviewed from the perspective of my Indian background, which will have instituted a non-Māori lens in the analysis. Also, this project was completed at KFCH, and the recommendations may not be entirely acceptable in other hospitals. The focus of this project mainly reviewed how Māori culture impact and influences the delivery of FCC. However, to develop an FCC charter, it would be advantageous to consider exploring other cultures, as in KFCH, we aim to provide care that embraces cultural diversity.

Conclusion

To conclude, culture holds immense significance when delivering FCC in New Zealand. Recent studies done in New Zealand acknowledge and highlight the significance of incorporating cultural awareness in daily practice. KFCH must urgently improve staff awareness on culture. This will enable them to provide culturally safe care in a culturally sensitive physical environment in consultation with children, young people, and families. By promoting respect for diverse cultural backgrounds, KFCH can guarantee that our service delivery is inclusive, respectful, and responsive to unique needs of our patients and families.

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Appendix A. Ethical Approval for quality project

Te Whatu Ora
Health New Zealand
Counties Manukau

12 April 2023

For the attention of: Julie Blamiers and Biby Kurian,

Thank you for the information you have supplied to the Te Whatu Ora Health NZ Counties Manukau Research & Evaluation Office to register this project:

Te Whatu Ora Counties Manukau Research Registration Number: 1740

Audit Study Title: "Practice project: Developing a family centred care charter for a paediatric acute care setting in NZ"

I am pleased to inform you that the Te Whatu Ora Counties Manukau Research & Evaluation Office has received all the required service lead approvals for the above study, which has you named as the Principal Investigator.

This Te Whatu Ora Counties Manukau locality approval is valid until 30 June 2023, which is the date specified on the study registration information.

Please note that failure to notify us of any extensions/amendments may result in the withdrawal of Te Whatu Ora Counties Manukau organisational approval.

We wish you well with your study.

FINAL REPORT: It is a requirement of the Te Whatu Ora Counties Manukau Research Policy that all research and audit projects conducted within Te Whatu Ora Counties Manukau should complete a Final Report within three months following completion of the study. The Final Report questionnaire can be found in your study file in the online Research Registry, under the Documents tab. This report will be viewable by all staff with access to the Te Whatu Ora Counties Manukau network. **Please Note** that having an overdue Final Report will impact your application for locality approval of any new studies.

Ngā mihi/Yours sincerely,



Angela Bennett
Locality Coordinator
Counties Manukau

Under delegated authority from Te Whatu Ora Counties Manukau Research Committee and the Chief Medical Officer

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Te Kāwanatanga o Aotearoa
New Zealand Government

Appendix B: Characteristics of Included Studies

Author (Year)	Country	Design	Sample	Data Collection	Findings	Relevance to project question
(Adcock et al., 2021)	NZ	Qualitative Phenomenology	19 Whanau	Interviews	<ul style="list-style-type: none"> • Preterm birth was an emotional roller coaster. • anticipated roles disrupted as health practitioners took over the care of their infants. • expressed desire to be close to their infants, holding them, loving them, nurturing them, and emplacing them within whakapapa (genealogy, continual layering of foundations) networks. • When health practitioners or hospital policies inhibited this intimacy by isolating, excluding, or discriminating, whanau were frustrated. • Being familiar with hospital routines, staff, peers, infant cares, and being wrapped in wider whanau support were key for whanau coping. • Whakawhanaungatanga (processes of establishing relationships) create safe spaces for whanau to be themselves. 	<p>Whanau is central concept for Māori- Māori families suggested what was important to them.</p> <p>Creating safe spaces and ability for whanau to be themselves and provide wrap around care is essential component within Whanau centered care.</p>
Aim: To give voice to the experiences, views, and attributions of whanau of preterm Māori infants.						

Author (Year)	Country	Design	Sample	Data Collection	Findings	Relevance to project question
(Crawford et al., 2017)	NZ	Focused ethnography	10 Nurses and 10 parents 238 informal interviews with parents and nurses during field work	Interviews Field work	<ul style="list-style-type: none"> • Parents of a child in hospital are isolated and vulnerable. • Nurses are unprepared to manage parents' emotion. • Parents want nurses to be the cultural brokers between parents and the hospital unit. • The context and culture of a hospital units influences nurse - parent communication • Unit organisations need to have embedded within them acknowledgment that meeting all parents' needs, including emotional concerns, is vital, and will improve the experience and health outcomes of parent and child. 	Adapting to child and families culture and engaging with parents to understand their emotions and their needs is a vital element in FCC. Culture of the hospital unit influences and shapes nurses behaviour.
Aim: To investigate nurses' experiences of emotional communication with parents of a child in hospital; to investigate parents' experiences of emotional communication with nurses in hospital; and to examine the environmental and cultural context within which the parent-nurse interaction occurs						
(Curtis et al., 2019)	NZ	Contextualised study Kaupapa Māori theoretical research	59 articles	Literature review	<ul style="list-style-type: none"> • Cultural competency and cultural safety in organisational level and health practitioner level is important for achieving health equity • Health care organisations to take responsibility to provide culturally safe care for the patients and their communities. • Cultural safety is important than cultural competency in achieving health equity. 	Health practitioners reflecting on their own culture to change their assumptions, biases, and power to become competent in other's culture and to provide culturally safe care.

Author (Year)	Country	Design	Sample	Data Collection	Findings	Relevance to project question
Aim: To understand the need for a shift from cultural competency to cultural safety for achieving health equity						
(Foster & Whitehead, 2017)	NZ	Descriptive qualitative cross sectional	91 parents And 66 staff	interviews	<ul style="list-style-type: none"> Both parents and staff acknowledged family as an integral part of FCC. Holistic approach is important in FCC. Families' involvement is pivotal for achieving good health outcome of the child. However, staff give priority for the medical and nursing treatment of child and the centre point is meeting the child's need rather than families. Building relationship and effective communication is a key element in FCC. Providing adequate live in facilities and resources for families by health care service is important to facilitate FCC. Child's perspective is not prominent in FCC, but staff put children and their needs at forefront rather than families. 	Importance of considering whole family involvement and meeting their needs not only concentrating on child's need. Effective communication and building relationship enhance the delivery of FCC. Cultural diversity impacts the staff's perception of FCC.
Aim: This study explored parent and staff perceptions of family centred care (FCC) within a paediatric high dependency in one New Zealand hospital.						
(Graham & Masters-Awatere, 2020)	NZ	Systematic literature review	20 articles	Qualitative meta synthesis	<ul style="list-style-type: none"> Māori patients and whānau from the mention both barriers and facilitators to health. 	For many Māori, the existing public health system is experienced as hostile and alienating.

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					<ul style="list-style-type: none"> Barriers a were categorised as organisational structures, staff interactions and practical considerations. Facilitators were categorised as the provision of whānau support in the form of practical assistance, emotional care and health system navigation. 	<p>Whānau members provide support to mitigate this, but it comes at a cost to whānau.</p> <p>Public health providers must find ways to ensure that Māori consistently experience positive, high-quality healthcare interactions that support Māori ways of being.</p>
Aim: To synthesise the broader perspectives of Māori patients and their whānau (extended family, family group) of their treatment within the public health system.						
(Masters-Awatere & Graham, 2019)	NZ	Narrative	15 families	interviews	<ul style="list-style-type: none"> positive engagement with culturally responsive social services had a positive impact on the health and well-being of whānau. Feeling culturally alienated exacerbates feelings of anxiety and worry while in hospital. consistent high-quality experiences with health professionals are required in order to overcome past histories of prejudicial and inequitable conduct. Families felt wider spiritual and cultural practices associated with their cultural identity were devalued within the mainstream health system. Hospital policies are not yet translated into culturally 	<p>Culturally safe positive engagement enhances the health outcome and wellbeing of whanau.</p> <p>Multiple positive interactions from health professionals are necessary to overcome the historical negative impression about health services.</p> <p>Developing health care policies with a culturally supportive lens will be beneficial for both clinicians and families.</p>

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					<p>supportive treatment in everyday hospital life.</p> <ul style="list-style-type: none"> Families are not comfortable about discussing the use of different Rongoā with their health practitioners. Families often ensure that their children's needs are met and they self-silence their needs. 	
<p>Aim: To explore the health-related experiences of whanau Māori with a child aged 0–5 years admitted to hospital. To understand if whanau Ora approach improved outcomes for the hospitalised child.</p>						
(Ministry of Māori Development, 2015)	NZ	Quantitative and Qualitative study using Participatory action research and Kaupapa Māori research.	200 monitoring reports from 34 collectives, 895 family surveys. 60 Action research report.	Survey and summary analysis. Qualitative meta-synthesis.	<ul style="list-style-type: none"> Placing whānau at the centre of service design and delivery not only empowers whānau to realise their own solutions; but also demands greater accessibility, integration, and coordination amongst service. whānau-centred approaches have a positive impact with immediate and longer-term benefits. whānau-centred approaches are a powerful catalyst for creating positive change. Five key factors leading to improvements for whānau are effective relationships that benefit whānau; whānau rangatiratanga, culturally competent and technically skilled workforce; services that 	<p>Family is considered as the central point in Māori culture. Empowering families to discover their own strengths, build confidence, and make choices and decisions about their health will improve participation in care and thus positive health outcome.</p> <p>Culturally appropriate health navigators play a vital role in establishing trust with whānau, guiding them to the appropriate services and offering necessary health education.</p>

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					place whānau at the centre; and funding, contracting and policy arrangements based on whānau priorities.	
<ul style="list-style-type: none"> Aim: To determine how whānau outcomes were being affected by whānau-centred services. 						
(Richardson et al.,2017)	NZ	Qualitative	16 public health nurses	Interviews and focus groups-inductive thematic analysis	<ul style="list-style-type: none"> Both verbal and non-verbal communication skills are fundamental to culturally safe nursing practice Weaving a culturally safe approach to practice enabled the individual and family to be empowered PHNs articulated an understanding of empowerment, recognising that they do not empower but rather facilitate the person to empower themselves. listening to client and family's stories is an essential element of cultural safety to avoid making assumptions. Cultural safety is not primarily about ethnicity 	<p>Culturally safe nursing practice enhances relationships and communication and thus improves wellbeing for the patient</p> <p>Culturally safe wrap around care will improve outcomes</p> <p>PHNs find innovative ways and means of engaging and connecting with people and families.</p> <p>Expressions of culturally safe practice have illustrated simple but effective ways to deliver care in a culturally safe manner</p>
Aim: To identify whether PHNs could utilise the 15-minute interview in their clinical practice, and how useful they found this.						
(Tipa et al., 2015)	NZ	Evaluation methodology	Phase one 50 nurses. Phase two	Online survey Observation interview	<ul style="list-style-type: none"> The Family Partnership Model (FPM) training appeared to improve nurses' confidence in working with Māori 	Ongoing support and training on cultural awareness for clinicians will help them to formulate the culturally appropriate questions

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			10 nurses and 10 families		<p>clients/whanau, participating in Māori community activities, and responding to whanau and community needs.</p> <ul style="list-style-type: none"> • FPM training is useful when building partnership with families, however, further work is needed to put this in practice especially when questioning their parenting skills or exploring their cultural backgrounds. • Family Partnership Model training, should also focus on exploring nurses' own socialisation, cultural identity, and values and beliefs that can impact on their practice and development of relationships. 	<p>and exploring the families cultural background when providing family partnership model care.</p> <p>Nurses understanding their own culture and belief will help them to build up culturally safe practice.</p>
Aim: Evaluation of the family partnership model nursing care implemented by Plunket nurses when engaging with Māori families are culturally responsive.						
(Wilson et al., 2021)	NZ	qualitative	10 articles	Literature review	<ul style="list-style-type: none"> • Culturally relevant and meaningful approaches to health care service delivery are critical for improving equity in Indigenous and other ethnic groups. • Relational approaches to engaging with Indigenous peoples and their families are cultural imperatives for accessing health services. • Culturally based health and wellbeing models provide 	<p>Two cultural values that inform how Māori interact with others are aroha (empathy and compassion) and Manaakitanga (kindness, generosity, and support to look after others. These cultural values are important and to be considered when developing policies and guidelines.</p>

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					important cultural values, concepts, practices, and processes essential for improving health outcomes	
Aim: Identify the key concepts, principles and values embedded within Indigenous Māori models of health and wellbeing; and determine how these could inform the development of a Māori-centred relational model of care.						
(Richardson et al., 2017)	NZ		16 nurses	Focus group	<ul style="list-style-type: none"> • Both verbal and non-verbal communication skills are fundamental to culturally safe nursing practice • Weaving a culturally safe approach to practice enabled the individual and family to empower themselves. • Both verbal and non-verbal communication skills are fundamental to culturally safe nursing practice. • Listening to client and family stories is an essential element of cultural safety in order to avoid making assumptions. 	<p>Culturally safe nursing practice enhance relationship and communication and thus wellbeing of the patient.</p> <p>Culturally safe wrap around care will improve health outcomes.</p>

Author (Year)	Country	Design	Sample	Data Collection	Findings	Relevance to project question
					<ul style="list-style-type: none"> <li data-bbox="1077 405 1498 549">Manners can be regarded as culturally constructed; what is considered well-mannered in one group in society might differ in another. 	
<p>Aim: Identify whether PHN could utilise Wright and Leahey's 15-minute interview with a concept of cultural sensitivity in their clinical practice.</p>						