



PHYSIOTHERAPISTS' AND MOTHERS' LIVED EXPERIENCES OF FAMILY-CENTRED
CARE FOR CHILDREN WITH PHYSICAL DISABILITIES IN SAUDI ARABIA:
AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

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ABSTRACT

Introduction

Family-centred care (FCC) is an approach for determining the best pediatric healthcare services for children and families. As families are an important part of a child's identity, healthcare providers must consider family dynamics, needs, and wishes when treating and supporting children. FCC has been explored worldwide; however, there is little knowledge about it in Saudi Arabia. Accordingly, this study examined the lived experiences of physiotherapists and mothers regarding FCC for children with physical disabilities in Saudi Arabia.

Methodology

Interpretative Phenomenological Analysis (IPA) was chosen to demonstrate how participants interpret a lived experience and make meaning of their personal and social reality. A face-to-face interview with open-ended questions was conducted with 8 participants (4 physiotherapists and 4 mothers of children with disabilities). Interviews were conducted in English and Arabic and lasted from 30 minutes to an hour and a half. A four-step analysis was carried out, following Smith et al. 's guidelines (2009). As IPA is idiographic, each interview was analysed individually, and then the process was repeated. To compare experiences, a cross-case analysis was done.

Findings

The mothers' and physiotherapists' experiences revealed five themes: 'current status of FCC within Saudi Arabia', 'roles of care and family dynamics in Saudi', 'communication as the cornerstone to FCC', 'the provision of support', and 'culture as a barrier to father's involvement'. FCC was unfamiliar to participants yet seen as different care. Saudi culture altered the division of caring roles, father engagement, and burden of care, which sometimes hindered family involvement and FCC provision. Communication, support, and information helped participants understand their children's conditions and rehabilitation, which improved their involvement in their children's care.

Conclusion

The study has provided new knowledge and understanding of FCC. The principles of FCC aligned with the Islamic values of Saudi culture, where some were reflected in the physiotherapist's clinical practice, but they were not explicitly recognised under a particular concept. Participants' experiences were heavily influenced by Saudi culture, which affects FCC provision and requires customising FCC to meet Saudi families' needs.

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Glossary of Abbreviations

FCC	Family-centred Care
CP	Cerebral Palsy
IPA	Interpretative Phenomenological Analysis
WHO	World Health Organization
MPOC-20, MPOC-28, MPOC-32	Measure of process of care for parents
MPOC-SP	Measure of process of care for Service Providers
HCP	Healthcare Provider
EI	Early Intervention
COPCA	Coping With and Caring for Infants with Special Needs
CBPU	Care-By-Parent Unit
PICU	Pediatric Intensive Care Unit
[JINN]	In Islamic culture, Jinn are invisible creatures composed of flame and smokeless fire that are capable of both good and evil. Jinn are able to assume a physical form and interact with humans; they can also possess humans and other creatures, causing them physical and mental harm.

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CHAPTER 1- INTRODUCTION

1.1 Introduction to The Thesis

This thesis explores the lived experiences of physiotherapists and mothers in Saudi Arabia regarding family-centred care (FCC) for the rehabilitation of children with physical disabilities. This chapter discusses the study's rationale as well as the gap in the literature that this research aims to fill. It sets the scene for family-centred care in the context of children's rehabilitation in Saudi Arabia. In addition, it provides an overview of the study's design along with the research question, aim and objectives.

As a licensed physiotherapist who has dealt with children with physical disabilities such as Cerebral Palsy (CP), Musculoskeletal Disorders and Spinal Cord Injuries, I have acquired expertise in treating these children. There is no doubt that these children are vulnerable and that their rehabilitation is crucial for their health and well-being. However, in my professional position, I have been forced to question the quality and efficiency of the physiotherapy treatments that I myself and other physiotherapists carry out on children on a regular basis. This motivated me to examine the lived experiences of physiotherapists and the parents of these children in family-centred care for the rehabilitation of children with physical disabilities in Saudi Arabia in order to gain an understanding of the existing state of rehabilitation services, how they are perceived and experienced by both families and physiotherapists and how they might be enhanced and evolved. Using interpretive phenomenological analysis (IPA) (Smith et al. 2009), I aimed to obtain a better insight into the lived experiences and meaning-making of the physiotherapists and mothers, as described in their own words. In this study, the age range used to represent children was 1-14 years, as this is the age range classified in Saudi Arabia as children, where pediatric healthcare staff, including physiotherapists, only serves children up to that age (Alnasser et al. 2022).

In this thesis, the historical development of the concept of FCC is investigated, including how it emerged and evolved over the years in nursing practice and how it has been adopted by various

healthcare professions. This thesis will also shed light on the concept of childhood disability, specifically within the context of Saudi Arabia. Furthermore, it will present the literature and studies that have examined the concept of FCC in different countries, given the novelty of the concept in Saudi Arabia.

1.2 Justification for The Study and Researcher's Stance

In recent years, there has been considerable interest in the concept of family-centred care as a socially constructed approach to the care of pediatric patients (Hill et al. 2017), that has numerous clinical implications for their rehabilitation and well-being. Kuo et al. (2012) defined FCC as the highest quality of healthcare received by parents that guarantees a collaborative strategy for making healthcare decisions about children with disabilities. Family-centred care is an evolving concept that has been extensively explored in other nations, such as the United Kingdom (UK), for over 60 years (Bamm and Rosenbaum 2007); however, it remains undefined in the context of Saudi Arabia. Despite its importance for clinical practice, the literature reveals very limited research on the mothers' and physiotherapists' lived experiences and perceptions of FCC for the rehabilitation of children with physical disabilities in Saudi Arabia.

It is feasible that the professionals who provide services for children with disabilities may have a different perspective to the parents of such children. The social structures within which individuals exist influence their interpretation of situations; therefore, individuals from different societies or groups within a society may have varying interpretations of similar situations (Seligman et al. 2017). Since family-centred care is a socially constructed approach (Smith and Coleman 2010), how it is implemented in Saudi Arabia may differ from how it is implemented in the UK, given that the different countries have different cultural backgrounds, cultural norms, family dynamics and different perspectives and understandings of care, all of which can influence the implementation of such an approach.

Specifically, in Saudi Arabia, children are considered to be integral members of their families which results in high expectations in terms of respect and care between children and parents. Children are raised with a culturally imposed lack of freedom of speech whereby they are generally not permitted to question or disagree with their parents; consequently, they grow up with limitations regarding their autonomy (Rajab and Wright 2017). When it comes to healthcare, including children's medical care, parents typically make medical decisions for their children, especially in the case of children with physical and cognitive disabilities. In fact, it is typical in Arab culture for the family to participate in health-related decision-making, resulting in a doctor-patient-family relationship rather than a doctor-patient relationship (Elislam 2005, cited in Loza and Omar 2017).

According to the researcher's knowledge of the Saudi healthcare system and its policies, most communication, interaction, and clinical decisions in paediatric rehabilitation settings are made by parents and physiotherapists, with minimal involvement from the child. Physiotherapists primarily rely on parents for information about the child's condition and treatment and they strive to teach parents how to manage and perform the exercises at home. In fact, the family is seen as the constant in a child's life because nurses view the parents and families as the decision-makers in the care of children and this is regarded as a crucial aspect of their practice (Alabdulaziz 2017).

In Saudi Arabia, the family remains the defining feature of social, political and economic life, and the family's obligations and relationships have not changed despite socioeconomic developments (Madi 2014). Since families continue to play an important role in the lives of Saudi children and, more importantly, in the rehabilitation of children with disabilities, it is crucial to understand how the parents of children with physical disabilities perceive FCC in order to comprehend their experiences, stances, perspectives and expectations of care. Because physiotherapists are part of the healthcare team working with children with disabilities and their families, their perceptions and experiences are also worthy of consideration. Therefore, it is necessary to consider both perspectives simultaneously as opposed to separately.

1.3 The Research Question, Aim, And Objectives

1.3.1 Research Question

What are the physiotherapists' and mothers' lived experiences and meanings of family-centred care for the rehabilitation of children with physical disabilities in Saudi Arabia?

1.3.2 Research Aim

The aim of this research was to explore the physiotherapists' and mothers' lived experiences and meaning-making of family-centred care for the rehabilitation of children with physical disabilities in Saudi Arabia.

1.3.3 Research Objectives

- To explore the personal lived experiences and meanings of physiotherapists and mothers of children with disabilities concerning family-centred care
- To explore the mothers' perceptions and meanings of the care received from physiotherapists in the context of family-centred care
- To explore the physiotherapists' perceptions and meanings of the care they provide in the context of family-centred care

1.4 Organisation of the Thesis

The thesis is divided into nine chapters, as described below:

CHAPTERS (1 AND 2) – INTRODUCTION AND BACKGROUND TO THE STUDY: This chapter sets the scene for the study and provides the structural context of childhood disability and the development of the concept of family-centred care.

CHAPTER (3) - LITERATURE REVIEW: Presents the literature review questions and the type of review conducted. It further outlines the search strategy employed, the databases searched, the inclusion-exclusion criteria applied and the quality assessment of the studies. It also presents the available literature on family-centred care, both globally and within the context of Saudi Arabia.

CHAPTER (4) - RESEARCH METHODOLOGY AND METHODS: Provides an overview of the methodological context and approach employed, a discussion of the methods, and an explanation of ethical considerations and justification for the use of IPA.

CHAPTERS (5 AND 6) - IDIOGRAPHIC EXPERIENCES AND CROSS-CASE ANALYSIS: Describes the individual participant's idiographic experiences of family-centred care and presents the cross-case analysis, which highlights the participants' shared experiences and any variations between participants.

CHAPTER (7) – DISCUSSION: Locates the mothers' and physiotherapists' experience in the wider context of FCC by discussing the results of current research with the literature and highlights the unique contribution of this study.

CHAPTER (8) – CONCLUSION: Provides an overall summary of the research. It also illustrates the study limitations, and the clinical implications of the study outcomes and presents recommendations for further research.

1.5 Conclusion

This chapter has established the research focus on exploring the meaning-making and lived experiences of physiotherapists and mothers on FCC for the rehabilitation of children with physical disabilities in Saudi Arabia. The chapter has presented an overview of the thesis structure and rationale for conducting this study. Furthermore, it has outlined the research question, aim, and objectives that will guide the investigation. The subsequent chapter will present an overview of childhood disabilities and the practice of family-centred care for children with disabilities within the context of Saudi Arabia.

CHAPTER 2- BACKGROUND TO THE STUDY: SETTING THE SCENE

2.1 Introduction

This chapter sets the scene by examining the definition of childhood disability, particularly focusing on the religious and cultural context of disability in Saudi Arabia, how disability is perceived, and how it is clinically addressed. Additionally, it provides an overview of the concept of family-centred care, its evolution, various definitions, and the underlying theories that have shaped its development. As mentioned in the previous chapter, FCC is a socially constructed concept, and to implement it within the framework of Saudi Arabia, understanding the cultural background of childhood disability and family dynamics in this context is essential.

2.2 Childhood Disability

According to the Saudi General Authority for Statistics, 2.54% of Saudi Arabia's children aged 0-14 years old have a disability (GaStat 2017). Based on their most up-to-date disability survey reports, 3.3% of Saudi Arabia's population of 31,742,308 people has a disability, with males being more likely to be affected than females: 3.8% versus 2.8% (GaStat 2017). According to the Convention on the Rights of Persons with Disabilities (CRPD), childhood disability includes those children with chronic, intellectual, physical or sensory disabilities which, when combined with other obstacles, can prevent them from participating fully and effectively in society (UNICEF 2022). During childhood, physical disabilities can result from brain damage, leading to medical conditions such as CP, epilepsy and developmental delay (Jan 2006; Mittler 2019). Furthermore, it can occur later in life as a result of a motor car accident or other health conditions, causing temporary or permanent impairments (Cooper et al. 2022). In addition to their distinct aetiology and clinical manifestations, these health issues can produce chronic non-progressive posture,

movement and cognition deficits that compromise the child's independence and lifestyle (Lissauer and Clayden 2007). Because the aetiology and severity of CP and epilepsy are dissimilar, there may be various treatment options for children with these conditions. This includes physical and occupational therapy, drug therapy to manage spasticity, and neurosurgery and orthopaedic intervention (Gulati and Sondhi 2017).

2.3 Islam and Disability

To understand the concepts of disability and inclusion, we must consider the particular context within which they are constructed; therefore, it is essential to comprehend what Islam means to Muslims when discussing religion and disability (Hassanein 2015).

For Muslims, Islam is not just a spiritual philosophy of life or a system of beliefs; it is a way of life (Al-Aoufi et al. 2012; Hassanein 2015). Therefore, the treatment of people with disabilities in Islamic societies is closely related to the five pillars of Islam. These pillars include the Shahada (the affirmation that Allah is God and Muhammad is His Messenger); the Salat (prayers performed five times a day); fasting during Ramadan; Zakat (a 2.5% tax on an individual's wealth); and Hajj (a pilgrimage to Mecca once in a lifetime) (Al-Aoufi et al. 2012; Hassanein 2015). The requirements for adhering to the five pillars of Islam depend on an individual's abilities, where Islam has granted various categories of individuals an exemption from specific duties and religious obligations (Ghaly 2016). For example, if a person with a disability is unable to attend prayer, they may have their prayers modified (Hassanein 2015). This indicates that Islam recognises the needs of and accommodates those with disabilities.

Islam fosters a positive attitude towards needy individuals, as the Qur'an and Hadith (the religious texts of Islam) contain principles and guidance for caring for those with disabilities (Al-Aoufi et al. 2012; Alenaizi 2019). It ensures that all members of society have rights, including people with disabilities, who are given equal consideration by the Islamic faith (Hassanein 2015;

Al-Aoufi et al. 2012). While the term 'disability' is not found within the Qur'an or Hadiths, these texts illustrate society's responsibility towards persons with disabilities to improve their living conditions, which are believed to be a result of the barriers created by society (Al-Aoufi et al. 2012; Alenaizi 2019). The holy book of Islam requires that every Muslim be considered a valued member of the community, regardless of a person's abilities or disabilities. The Qur'an mentions in ten verses that persons with disabilities should be treated with full consideration and have the same person-to-person relationships among themselves as those without disabilities (Hassanein 2015).

The Qur'an outlines a concept of 'guardianship' that involves honouring, being fair to and treating with kindness disadvantaged individuals, and this includes the provision of food, clothing, housing and protection, which all fall under social responsibilities (Al-Aoufi et al. 2012). Integral to its emphasis on distributive justice, the Qur'an instructs Muslims to donate a small percentage of their income to charity or Zakat for the poor, vulnerable, and deserving, for example, individuals with disabilities, to ensure their rightful share (Al-Aoufi et al. 2012). This demonstrates that the Islamic religion does offer a framework for caring for people with disabilities by presenting the requirements for Muslims to follow.

Although the teachings of the Qur'an, the Sunnah (the practices and traditions of the prophet Mohammed that serve as a guide for Muslims to follow) and the Hadith suggest that people with disabilities are to be accepted and tolerated, cultural attitudes and beliefs are not always influenced by these teachings. Indeed, disability has been seen as both a blessing that has religious and moral significance in some Muslim countries and as a test of faith under Allah's command (Al-Aoufi et al. 2012; Alenaizi 2019). As Al-Aoufi et al. (2012) argue, when religious values meet cultural perspectives, it can result in different courses of action, sometimes mistakenly attributed to religion, for example, embarrassment at having a child with a disability and attempting to explain the cause of childhood disability. Yousef (2018) suggests that the way Islam and culture shape perceptions of disability is very complex and may be influenced by national cultural differences as well as the local conditions in which people with disabilities live. It is, therefore, imperative that the perception of disability in Islam be taken into account when

reviewing special education policies, facilities and services (Yousef 2018), as Saudi Arabia is a Muslim country.

2.4 Saudi Arabia and Disability

Saudi Arabia holds a unique position in the Islamic world as it is the place where the religion of Islam originated and where the holy mosques are located (Alariefy 2016). Furthermore, The Saudi Arabian healthcare practice adheres to a set of codes of conduct that are based on the Islamic religion, Sharia (SCFHS 2019). The term Sharia refers to a comprehensive system for defining ethical, religious, and legal principles related to life and forms the basis of Islamic law and values (SCFHS 2019). Disability in Saudi Arabia is viewed through the prism of Islamic Sharia, cultural norms and legislative provisions, and since the Qur'an and the Sunnah are the foundation of Islam, disability is often viewed through the lens of the religion. These moral codes of ethics recognise the role of the family as an important part of the decision-making process and encourage healthcare providers to deliver services that respect Islamic cultural norms and the physical and emotional well-being of patients and families (SCFHS 2019).

2.4.1 Disability and Cultural Beliefs

The influence of culture on the lives of those with disabilities in Saudi Arabia is demonstrated in the following studies. Al-Jadid (2013) and Alkohaiz (2018) reported that many people with disabilities in Saudi Arabia suffer from marginalisation. This has resulted in their disenfranchisement for various reasons, including ignorance of disabilities, fear of disability, shame at the idea of being involved in their community, a lack of understanding regarding ways to deal with such cases, and ignorance of the role of health facilities (Al-Jadid 2013). It has been argued that the conservative nature of Saudi society perpetuates these views (Al-Aoufi et al. 2012). Conservatism is especially prevalent in many smaller rural villages, towns and provinces,

whereas cities have greater international exposure and are consequently less socially conservative (Alshiakh 2022).

Yousef (2018) proposed that cultural and Islamic perspectives on disabilities also shape perceptions of disability. In fact, Al-Jadid (2013) and Al-Aoufi (2012) highlighted that culture, religion, and other factors actively protect the current situation for people with disabilities in Saudi Arabia. Specifically, those with developmental, intellectual, or psychosocial disabilities are particularly stigmatised as sources of shame and burden (Yousef 2018). Disabilities are often regarded as shameful, financially burdensome for families, or even a curse, and are typically characterised or conveyed in negative or derogatory terms, with individuals being identified or labelled by their disability (Al Thani 2007). Cultural attitudes toward people with disabilities also encompass prejudices, such as attributing childhood disabilities to a mother's sin, a curse, or demonic possession (Al-Gain and Al-Abdulwahab 2003). In fact, Madi et al. (2019) found that mothers held diverse cultural and religious explanations for their children's disabilities, with some attributing them to the influence of evil spirits [Jinn].

2.4.2 Saudi Arabia's Disability Legislation

The priority of the Saudi government is to provide a decent standard of living for its citizens and residents, considering the needs of various groups, particularly individuals with disabilities, and ensuring that the legislative system for individuals with disabilities protects their rights (The Bureau of Experts at the Council of Ministers 2021).

The Saudi Arabian Basic Law of Governance outlines the legal foundations concerning people with disabilities, addressing aspects such as social welfare, rehabilitation, and healthcare services (The Bureau of Experts at the Council of Ministers 2021). Articles 23 to 43 of Part 5 of the Basic Law govern rights and duties within Saudi Arabia. Article 26, on page 7, stipulates that, "*The State shall protect human rights in accordance with the Islamic Shari'ah.*", emphasising concepts of justice, equality, and the prohibition of discrimination, including disability. Consequently, the

Saudi government is dedicated to ensuring that all human rights in Saudi Arabia are protected in accordance with Shariah law. In fact, Article 27, on page 7, provides that:

"The government guarantees the rights of the citizen and his family in case of emergency, illness, disability and mental retardation, and supports the social security system and encourages institutions and individuals to voluntarily participate in the welfare programmes."

In 2000, the Saudi government passed the Disability Code, a piece of legislation aimed at protecting the rights of people with disabilities (The Bureau of Experts at the Council of Ministers 2021). Al-Jadid (2013) states that the goal of the Disability Code is to assure people with disabilities that they will receive appropriate rehabilitation, medical treatment, education and social services from the government.

Persons with disabilities are defined in Article I, page 3 of the Disability Code as:

"One who is totally or partially disabled with respect to his/her bodily, material, mental, communicative, academic or psychological capabilities, to the extent that it compromises the ability of that person to meet his/her normal needs as compared to his/her non-disabled counterparts".

Disability in this context is broadly defined to include mental, psychological, and academic abilities (The Bureau of Experts at the Council of Ministers 2021). Additionally, Article 2, Page 3, of the Disability Code reinforces this principle by stating that the government shall provide protection, welfare, and rehabilitation services to people with disabilities and their families. Prevention is therefore defined as:

"The set of medical, psychological, social, educational, informational and regulatory procedures, which aim at preventing or limiting the effect of disabilities and at pre-empting and easing the consequences thereof." (The Bureau of Experts at the Council of Ministers 2021).

Accordingly, on pages 3 and 4, welfare encompasses not only "care services for people with disabilities based on the extent of their disabilities" but also "medical and social services for them." Additionally, rehabilitation encompasses a holistic approach, enabling them to achieve the greatest degree of functional efficiency by utilising medical, psychological, educational and professional services (The Bureau of Experts at the Council of Ministers 2021).

2.4.3 Saudi Disability Services

There is evidence that disability services in the Kingdom of Saudi Arabia have a significant impact on the lives of individuals with disabilities, as these services include both health and social services (Al-Jadid 2014; Aleisa et al. 2014). In fact, the Saudi Arabian government has established numerous disability services, but most of them focus primarily on providing medical and therapeutic services within the healthcare system (Al-Jadid 2014). This rehabilitation encompasses a multitude of services, including medical rehabilitation, physical, psychological, speech, and occupational therapy (Aleisa et al. 2014). As part of rehabilitation services, people with health conditions who experience or are likely to experience disability are given a chance to regain and maintain optimal functioning and interaction with their environment (Aleisa et al. 2014). This includes providing early childhood care to children with disabilities, such as preschool programs, special care, education, and social services, all of which contribute to the effective development of a child's physical, social, emotional, and intellectual abilities (The Bureau of Experts at the Council of Ministers 2021).

Despite the government's efforts to provide people with disabilities with appropriate services, challenges related to organisational structures and resources still persist (Almalki et al. 2012).

According to their study, Saudi Arabia has limited staff training programmes and disability awareness campaigns designed to improve the lives of those with disabilities. In a similar vein, Aleisa et al. (2014) highlighted the deficiencies of one of Saudi Arabia's university hospitals, including the lack of effective collaboration between rehabilitation staff and other departments, the limited number of rehabilitation research studies, the poor IT systems, weak administrative and organisational systems, and limited financial incentives for staff. This implies that, in light of these shortcomings in big city hospitals, the standards and quality of services in rural hospitals which serve smaller communities and villages may be called into doubt.

2.5 Family Dynamics and Disability

2.5.1 The Saudi Family Dynamics

While an adaptation to a disability is profoundly influenced by the cultural environment of a family, the objective of this section is to provide an overview of the Saudi family structure and functions (Seligman et al. 2017). According to the Saudi constitution, Article 9, page 4

“The basis unit of the Saudi society is the family; its members shall be brought up on the basis of Islamic creed and its requirement of allegiance and obedience to Allah, to His Messenger, and to those in authority, respect for and implementation of laws, and love of and pride in the homeland and its glorious history.”

This statement highlights the significance of the family unit within Saudi culture. Indeed, Seligman et al. (2017) state that family functions play a fundamental role in the way a family responds to medical care and how families find meaning in having a child with a disability. A cultural feature of Saudi Arabia is the extended family unit, which consists not only of husband

and wife but also of children, adult children, adult children's spouses, and grandchildren (Al-Saif 1991). An extended family usually consists of three generations, with the grandfather serving as the authority figure in the extended family (Achoui 2006). Large extended families frequently reside in one house because families are close-knit, with less attention paid to personal autonomy and independence (Al-Gain and Al- Abdulwahab 2003). As a result, Saudi Arabians expect very close relationships and accept familial obligations, which ensure harmony and individual identity for the family members (Al-Saif 1991). Thus, individuals with disabilities are cared for by their families instead of being institutionalised (Madi 2014).

In Saudi Arabia, family honour is a central matter which determines the norms of male-female relationships, with men's honour being related to their responsibility to support their kin economically, legally and morally (Al-Rasheed 2013). Saudi society shares a number of traditional gender roles with other societies, including the fact that men's primary role is to provide, protect and manage their families, while women take care of the home (Madi 2014). Men are more likely to work outside of the home in business and public affairs, whereas women are more likely to make decisions within the home, particularly regarding parenting matters. Indeed, according to the Saudi General Authority for Statistics (2017), fewer than 15% of Saudi women over the age of fifteen years old are employed, which is a very low female labour force participation rate. This could be attributed to the custom of guardianship in Saudi Arabia which typically gives husbands the final say on decisions about their wives' work (Bursztyn et al. 2020). However, with the new Saudi 2030 Vision (a programme aimed at empowering women and calling for equality in the workplace), the legal system of guardianship will be phased out. Consequently, it is anticipated that gender roles will change as a result of this rapid modernisation (Vietor and Sheldahl-Thomason 2018).

Saudi Arabian families are generally quite large compared with a typical Western family, where close personal relations exist between families and relatives, and there is much effort made to maintain stable personal relations (Madi 2014). In fact, the Saudi population is growing at a rapid rate due to the socio-economic changes that are occurring, and, due to the rapid growth rates, an average Saudi Arabian family is composed of 7 individuals, ranging between 7.5 in rural areas and 6.8 in urban areas (Madi 2014). This has led to an increased need for economic support, with

a focus on enhancing employment and income opportunities, improving social care and services, and reorganising social structures in a way that benefits children and youth during their critical growth and dependency stages (The Ninth Development Plan 2021-2025).

Despite modernisation, the extended family in Saudi societies remains the most influential element of Saudi social, political, and economic life, and the family's role toward children or parents or the family's duties and ties have not changed (Madi 2014). The Saudi Arabian cultural values do not appear to have been affected by this change, as families still play a crucial role in the lives of their children, daughters, and sons (Madi 2014). This requires that relatives and elderly parents are supported by each other, and this remains a habit in Saudi Arabian families that is bonded to religion.

In Islam, many elaborate texts encourage interaction between people and their neighbours, family and relatives, where maintaining a good relationship with relatives is a duty and severing this connection is unacceptable (Salamah 2017). In fact, it is considered disgraceful for parents to be placed in a nursing home in Saudi culture and it is the family's duty to care for divorced or widowed daughters or sisters (Al Rubiyea 2010). It can be inferred from the above that family plays an important role in a Saudi child's life and a greater role in the rehabilitation of a child with a disability in Saudi Arabia.

2.5.2 The Impact of Disability on Family Dynamics

Chronic or severe illness unavoidably disrupts a family's equilibrium and balance as the strain of caring for a child with a disability increases with the progression or regression of the child's medical condition (Bamm and Rosenbaum 2008). This can lead to significant social and emotional stress on the parents of special needs children, as reported by Jung-Hwa et al. (2011). Indeed, studies demonstrate that providing additional care for children with disabilities can disrupt family functioning and bonding, resulting in marital conflict (Haimour and Abu-Hawwash 2012; Kazmi et al. 2014).

There is evidence that having a child with a disability also affects the child's siblings who may endure challenges and stress due to having a sibling with a disability in the household. Hodges (2016) reported that siblings of children with cystic fibrosis experience emotional labour by highlighting instances of chaos and complexity that they encountered. In their accounts, siblings described a variety of unpleasant emotions including grief, anxiety, worry, uncertainty and frustration (Hodges 2016). In addition, those who lived with a sibling with cystic fibrosis exhibited evident emotional distress associated with their sibling's diagnosis and/or the deterioration of their illness as well as feeling separated from their mothers when such changes occurred (Hodges 2016 and Hodges 2018).

Acknowledging that caregivers of children with disabilities are vulnerable individuals with increased caregiving responsibilities, the public health system has an even greater need to provide them with care and support, as well as take steps to safeguard their well-being (Vadivelan et al. 2020). Moreover, Purpura et al. (2021) emphasised the importance of delivering rehabilitation and educational services that foster a positive relationship between the child and their parents by taking into account the child's family needs and enhancing psychosocial support for parents.

2.6 Family-Centred Care

The following section explains why family-centred care was chosen for the current research. It presents an overview of the perspective and evolution of FCC in the UK, where I, the researcher, studied, and compares it to the perspective and evolution of the concept in Saudi Arabia, where data collection was conducted. Family-centred care was selected for the current study as it was considered better suited to the culture and circumstances of Saudi Arabia, where family plays a vital role in Saudi life, from childhood to adulthood. Additionally, since physiotherapists worldwide are increasingly adopting family-centred care concepts to support the rehabilitation of children with disabilities, this notion of care was chosen as the phenomenon of interest for this study. This was examined in light of the lived experiences and meaning-making of mothers

and physiotherapists within the Saudi rehabilitation context to gain a better understanding of the phenomenon.

2.6.1 The Evolution of Family-Centred Care

In the United Kingdom, family-centred care originated in acute settings, while in North America, it developed in social settings for children with special needs (Smith and Coleman 2010). The responses of nurses and parents have also played a role in shaping and influencing the concept's development over time (Jolley and Shields 2009). This demonstrates that family-centred care has continually evolved, impacted by the beliefs and actions of the culture in which it has been practised; thus, it has different definitions based on the society in which it has emerged (Bamm and Rosenbaum 2007). As the concept continues to evolve and expand in Britain and other countries, several factors contribute to its development, including recent societal and policy changes, the emergence of theories supporting family-based care, and the responses of nurses and parents to these concepts (Bamm and Rosenbaum 2007, Smith and Coleman 2010).

Since the 1950s, FCC in the United Kingdom has been continuously advancing and progressing in the field of pediatric healthcare (Gray 2015), FCC development was significantly affected by the historical events that occurred before and after that period (Smith and Coleman 2010), where it underwent a process of modification after World War II (Krajnc and Berčan 2020). The preceding events demonstrate a transition from sick children being cared for at home by their parents to a system of routine hospitalisations which resulted in the exclusion of parents (Jolley and Shields 2009, Franck and O'Brien 2019). In fact, it was not until the nineteenth century that hospitals for sick children began to arise, forcing the separation of mother and child (Gooding et al. 2011). At that time, childhood and adulthood were barely distinguishable from each other due to the social construction of childhood, with much emphasis placed on fulfilling the physical needs of sick children than their psychological needs (Jolley and Shields 2009, Smith and Coleman 2010). Strong child-rearing ideas that neglected parental presence dominated hospital care of children

until the 1950s, when a psychological approach to family-centred care emerged as children's emotional needs became apparent (Smith and Coleman 2010).

This was addressed in the Platt Report (Ministry of Health and Central Health Service Council, 1959), whose recommendations emphasised the psychological well-being of the hospitalised child by permitting parents to see their hospitalised children at their convenience (Barnsteiner et al. 2014). Unfortunately, the implementation of such recommendations was slow because some nurses, particularly those who considered parental involvement as a negative step, fought parental presence (Smith and Coleman 2010; Barnsteiner et al. 2014). Despite this, successive governmental and organisational initiatives continue to advocate for family involvement in children's care in hospitals and at home, urging nurses to adopt a family-centred care approach (Smith and Coleman 2010; Gray 2015).

During the early phases of the theoretical development of FCC, the presence of caregivers in hospitals with their ill children was incompatible with the treatment of children in hospitals (Smith and Coleman 2010). There was frequent resistance to parental attendance, and it was not always actively encouraged since nurses feared losing their authority to parents. Hawthorne (1974) contributed to the philosophy of FCC by presenting it early on, since his study demonstrated the necessity to teach nurses about the emotional needs of children and to encourage the presence of parents on the ward. Most nurses accepted the presence of parents with their children in hospitals by the 1980s after receiving training on the emotional needs of children (Smith and Coleman 2010). Within this social construct, family-centred care has been modified so that parents may be more actively involved in their child's care, as opposed to being only passive. There has been an increase in parental involvement in newborn care over the years, with a growing realisation that parents play a crucial role in enhancing the health outcomes of preterm infants both in and out of the hospital (Franck and O'Brien 2019).

The current social construction of FCC for children is widely acknowledged in the United Kingdom and worldwide in the twenty-first century, as evidenced by an examination of shifting social structures, events, and legislation (Jolley and Shields 2009; Smith and Coleman 2010). Globally, family-centred care has evolved in a similar manner. According to Shields (2001), there are

significant differences in FCC practices between developing and developed nations since nursing literature from developed nations demonstrates that parents are permitted to remain in hospitals while their children are receiving care. While the limited literature available in developing countries encouraged parents to stay with ill children (Shields 2001). Additionally, in some places, parents were excluded or experienced restricted visiting, but there were a few developments in terms of innovative ways to involve parents in the care process (Shields 2001).

2.6.2 Definitions of Family-Centred Care

According to Franck and O'Brien (2019), FCC refers to the philosophical framework and set of guiding principles and values that inform the delivery of healthcare to families. There are numerous definitions and characteristics of family-centred care in the literature, all of which recognise the essential role that family plays in the life of the child. Franck and Callery (2004) described these attributes as involving parents in their children's healthcare, especially in decision-making, allowing families to function within healthcare settings, and caring for family members as well as children.

In supporting this notion, Gagné-Cleveland (2006) states that family-centred care involves a collaboration between patients, their families, and healthcare providers in order to achieve the best possible plan of care and promote optimal functioning. Furthermore, families should benefit from a collaborative, non-judgmental relationship based on shared decision-making, where they can negotiate their desired level of involvement (Smith and Coleman 2010).

The Institute for Patient and Family-centred Care (1992) in the United States defines family-centred care as the process of coordinating, planning, delivering and evaluating healthcare in which providers, patients and family members work together for mutual benefit (Johnson and Abraham 2012). This implies that the concept can be applied to any healthcare setting, and it is applicable to patients of all ages (Smith and Coleman 2010). Similarly, Shields et al. (2006) define FCC as a method of providing health services for children and their families that focuses

on the entire family and not just on the individual child and that recognises the entire family as the recipient of the services.

The American Academy of Pediatrics (2012) defines patient- and family-centred care as care based on the understanding that families are the primary source of strength and support for children. Patient- and family-centred care is an approach to healthcare that involves planning, delivering, and evaluating healthcare grounded in collaboration between patients, their families, and providers, recognising the family's contribution to the patient's health. This practice influences the design of healthcare facilities, policies, and programs, as well as daily interactions between patients, families, physicians, and other healthcare professionals.

In Canada, CanChild (1989) defines family-centred services as follows: an approach to providing services to children with special needs and their families based on a set of values, attitudes, and approaches (King et al. 2002). Families are regarded as unique, constant in a child's life, and as experts concerning a child's abilities and needs. Alongside service providers, the family makes informed decisions regarding the support and services the child will receive. Family-centred services consider the strengths and needs of each family member (King et al. 2002).

In light of these definitions, family-centred care refers to an approach to children's care that acknowledges the essential role of the family in children's care, a concept articulated and discussed in previous literature. The family-centred approach emphasises patient and family participation in making informed decisions about the medical care, treatment, and support services they receive jointly (Franck and O'Brien 2018). Furthermore, the goal is to improve psychological well-being, clinical outcomes, and the overall experience of the patient and their family by involving and supporting them throughout the process of childcare (Franck and O'Brien 2018).

2.6.3 Theoretical Framework for Family-Centred Care

2.6.3.1 Functional and holistic frameworks for family-centred care

The functional framework is presented by Nethercott (1993), which is a nurse-led approach that lacks collaboration, in which nurses assume the gatekeeper role and make decisions regarding the extent of parental involvement in care (Hutchfield 1999). Parents and families are considered disempowered by this approach since the nurses retain the authority (Smith and Coleman 2010).

On the other hand, a holistic view advocated by Hutchfield (1999) empowers children and families more effectively, in which family-centred care is based on respect for and collaboration with the family. This framework was intended for children with special needs and their families, and this approach positions the nurse functions as a facilitator of care for the child as well as an equal partner, considering the values and priorities of each family when planning care (Smith and Coleman 2010). Additionally, this framework emphasises the importance of exchanging sufficient and unbiased information with families. Although both frameworks are fundamentally different due to their various underlying philosophies, Smith and Coleman (2010) suggested that communication can be considered a feature that both approaches share, albeit used differently, as the holistic approach promotes more open communication than the functional framework.

2.6.3.2 Hierarchical frameworks

A hierarchical framework for family-centred care was offered by Hutchfield (1999). This consists of four levels of care, with involvement at the lowest level, moving up to participation, then partnership and finally reaching family-centred care at the top (Smith and Coleman 2010). These levels differ based on the type of relationship, belief about the parent and family, level of care characteristics, communication needs and identification of both parental and nursing roles (Hutchfield 1999).

This framework recognises the right of families to contribute to their child's care at a level that fits their preferences (Hutchfield 1999). However, it has been argued that the framework implies that progression is one way and does not appear to acknowledge the fact that the level of care a family may wish to provide for their children may vary over time (Smith and Coleman 2010).

2.6.3.3 Communication frameworks

Communication is considered a pivotal component of a family-centred care model that must be considered throughout the care provision process (Krajnc and Berčan 2020). There are two communication models, as referred to by Smith and Coleman (2010), which are the LEARN framework for communication and The Nursing Mutual Participation Model. Although healthcare professionals are free to follow any FCC model they choose, these communication models define guidelines for practice that must be considered in order to achieve FCC.

The LEARN model emphasises the importance of parents and nurses communicating clearly and listening carefully to each other before negotiating an infant's care to avoid misunderstandings and misinterpretations. The Nursing Mutual Participation Model uses open-ended questions in an attempt to discover what the child and family feel they can do in respect of participating in care in order to meet the child's needs since the professional alone cannot know what the child needs (Ahmann 1994, p. 115 cited in Smith and Coleman 2010). In order to implement the holistic view of family-centred care, some model of communication needs to be incorporated into clinical practice.

2.6.4 Family-Centred Care: A Practice Continuum

Rather than adopting a hierarchical approach to family-centred care where parent-led care is seen as the ultimate goal, Smith and Coleman (2010) suggested using a practice continuum, in which parents can choose their level of involvement in care. The strength of the continuum tool,

according to Smith and Coleman (2010), lies in its ability to respond to individual needs as a child's and family's circumstances change during their child's care. Nurses can move forwards or backwards along the continuum to accommodate these changing circumstances. By employing the Practice Continuum, nurses can cater to individual needs within a range, as opposed to using a blanket approach that may not always be applicable (Smith and Coleman 2010). Smith and Coleman (2010) state that the functional approach, holistic framework, communication framework, and hierarchy framework can be incorporated into family-centred care when viewed as a Practice Continuum.

No involvement	Involvement	Participation	Partnership	Parent / Child Led
Nurse Led	Nurse Led	Nurse Led	Equal Status	Parent / Child Led

Figure 1 Smith and Coleman (2010) practice continuum, p. 42

The practice continuum, as suggested by Smith and Coleman (2010) (Figure1), consists of five levels of care, which are as follows:

- Nurse-led care, No Involvement: This might be the case when the family is not able or willing to participate for a certain timeframe for whatever reason. Separation of parents from their children at birth because of medical reasons is one example, and in some cases, child protection issues may prevent parental involvement.
- Nurse-led care, family/child involvement: Family involvement occurs when a caregiver performs tasks normally associated with a parent's role, like hygiene, feeding and emotional support. Negotiations with parents are led by the nurse at this stage in care management.
- Nurse-led family/child participation in care: A family member or child may assist with aspects of nursing care that are usually ascribed to nurses, such as administering medications, which is arranged in advance with the parents. Throughout the care process, the nurse supervises

the management of the child's care and, where necessary, teaches the family appropriate care skills.

- Equal status, family/child partnership in care: The nurse's role changes from being one of support to one of facilitator, and the relationship becomes more equal as families reclaim their roles as primary caregivers.
- Parent/Child-led care, nurse-consulted care: Where families are the most knowledgeable about the child's needs and care and require the presence of a mutually respectful relationship with the nurse, who provides consultation from time to time.

At all levels of the continuum, open communication between parent and nurse is essential in order to foster the relationship (Krajnc and Berčan 2020), and both sides need to be honest about their limitations without fear of failing (Smith and Coleman 2010).

2.6.5 Models of Family-Centred Care

Various models of care in the healthcare field are considered when addressing the care of children with disabilities, which can aid nurses and other healthcare professionals in their practice. Given the diversity of healthcare models, understanding their differences is essential. Thus, a brief overview of these models is provided below.

In their recent review, Kokorelias et al. (2019) identified 55 models of family-centred care designed for an array of care contexts (e.g., community and acute care) and involving various healthcare professionals. The care contexts encompassed home and community-based care, acute hospital wards, emergency departments, critical care units, inpatient rehabilitation units, and palliative care units. These models featured a range of healthcare professionals, such as nurses, social workers, physicians, psychologists, and rehabilitation therapists. The study found that the core elements of FCC models did not differ based on diagnosis, age, or care context, suggesting that some principles of FCC models are shared universally (Kokorelias et al. 2019).

2.6.5.1 The core principles of family-centred care

To fully comprehend the concept of FCC, it is imperative that its underlying principles are understood. Family-centred care includes a number of core concepts, some of which might be shared across institutions.

❖ The Institute for Patient and Family-Centred Care

As an example, the Institute for Patient and Family-centred Care identified four core concepts within this Western concept (Johnson and Abraham 2012), including the following:

- Dignity and respect: Patients and their families are treated with dignity and respect by healthcare professionals who listen to their perspectives and choices. In the process of planning and delivering care, patients' and families' knowledge, values, beliefs and cultural backgrounds are taken into consideration.
- Exchange of information: Healthcare professionals provide patients and families with accurate, complete and unbiased information in an affirming and helpful manner. Information is provided to patients and families in a timely, complete and precise manner to help them make informed decisions and participate in the care process.
- Participation: Participation in care and decision-making is encouraged and supported to the extent that the patients and families choose.
- Collaboration: This includes developing, implementing and evaluating policies and programmes, designing facilities, educating healthcare professionals and conducting research in partnership with patients, their families and healthcare practitioners.

❖ The American Academy of Pediatrics: Policy Statement

In their policy statement, the American Academy of Pediatrics identified six core principles to family-centred care, which formulates clinical practice (2003), and this includes:

- Respect: Having respect for each infant and their family by honouring the diverse racial, ethnic, cultural and socioeconomic characteristics of families and their different experiences and perceptions of care. Additionally, identifying and building on each infant's strengths, regardless of how challenging the situation may appear, by facilitating and supporting the infant's and family's choice.
- Flexibility: Providing services that are tailored to each family's needs, beliefs and cultural values using organisational policies, procedures and practices.
- Information Sharing: Providing families with accurate, unbiased and helpful information on a regular basis.
- Support: Providing families with formal and informal support to assist in their full participation in the care of their infants prior to, during and following their hospitalisation in the NICU.
- Collaboration: Establishing a collaborative relationship with families at all levels of healthcare for the care of infants and the development of healthcare policies, programmes and education at the institutional level.
- Empowerment: Enabling families to recognise their own strengths, gain confidence and make informed decisions regarding their healthcare and that of their infants.

❖ CanChild Centre for childhood disability research

According to the CanChild Institute, the philosophy of family-centred service acknowledges that parents are experts on their children's needs, fosters partnerships between service providers and parents, and promotes family involvement in the decision-making process concerning services for their children. This approach encompasses the following principles:

- The provision of supportive and respectful treatment
- The provision of coordinated and comprehensive care
- The provision of enablement and partnership services

- The provision of general information
- The provision of specific information regarding the child

From the above, it can be inferred that there are common principles of family-centred care across a variety of institutions; all of which emphasised the importance of providing care that is based upon respecting the uniqueness, needs and desires of each family and providing coordinated and supportive care in such a way that enables family empowerment and partnership in the care of children.

2.7 Summary

Family-centred care has evolved over time due to various societal shifts. The theory of FCC has gradually developed, with the focus of studies transitioning from early investigations on the effects of separating mother and child to contemporary research exploring family processes and the involvement of children and young people in care and decision-making (Smith and Coleman 2010). Although family-centred care is a concept that continues to evolve in the UK and globally, perceptions of it in the UK may differ from those in Saudi Arabia. As a result, it is essential to conduct this study to examine FCC within the Saudi Arabian context, laying the foundation for its evolution, underlying theories, and practical application in clinical rehabilitation.

Given the significant number of children with disabilities in Saudi Arabia, the prevailing belief that FCC is the optimal approach to their care (Kuo et al. 2012), and the World Health Organisation's recommendation for its application (2012), it is crucial that healthcare providers comprehend FCC and how to implement it. In fact, by exploring the experiences and perspectives of physiotherapists and families of children with physical disabilities, it will be possible to evaluate the relevance of family-centred care for implementation in paediatric rehabilitation and determine how it could be achieved in Saudi Arabia.

CHAPTER 3 – LITERATURE REVIEW

3.1 Introduction

This literature review section aims to provide an understanding of how studies have investigated the concept of family-centred care for the rehabilitation of children, as well as the experiences of mothers and physiotherapists working in this field. The following section outlines the type of review conducted, the search terms employed, the quality of papers included, and the inclusion and exclusion criteria. Furthermore, it comprises a review of current research and literature on FCC for children with disabilities.

3.2 Literature Review Questions

Three key questions underpinned this literature review and shaped the subsequent search strategy, as follows:

- *How is family-centred care perceived by parents and physiotherapists in a rehabilitation setting in Saudi?*
- *How is family-centred care experienced by parents of children with disabilities and by physiotherapists who treat children with physical disabilities in Saudi Arabia, and what are the meanings entitled to these experiences?*
- *What are the clinical implications of applying FCC to pediatric rehabilitation?*

3.3 Type of Review

Given the limited literature on FCC for the rehabilitation of children with disabilities in Saudi Arabia, this study sought to examine family-centred care in a broader context using a narrative review. The narrative review approach was employed, as it identifies gaps or inconsistencies within the body of knowledge and draws conclusions based on literature analysis and synthesis (Dudovskiy 2018). Literature was searched using the keywords highlighted in section 3.4 to encompass all available literature concerning FCC.

3.4 Search Strategy

An electronic search was undertaken between October 2018 and April 2019, prior to the submission of the research proposal, using the following databases: PubMed, Medline via Ovid, AMED, CINAHL via EBSCO, ScienceDirect, and Scopus. The search was updated during October 2022 and December 2022, and March/April 2023. Specifically, the scope of the study was to explore the physiotherapist's and parents' lived experiences and the meaning of FCC for the rehabilitation of children with physical disabilities in Saudi Arabia. Although the primary focus was on FCC in the rehabilitative setting of Saudi Arabia, there was a lack of literature around it in this context, and the literature presenting the Saudi Arabian perspective on FCC was limited to other healthcare professions such as nursing and medicine. Therefore, I chose to explore FCC for the rehabilitation of children with disabilities in the wider context and the following literature review thus gives a worldwide perspective on family-centred care for children in rehabilitation to capture as much information as possible on FCC as a concept for children's rehabilitative care.

3.5 Databases Searched and Keywords Used

The table below (Table 1) displays the health databases searched for this research, as they contain medical, nursing, and allied health professions literature, which is most relevant to the scope of this study. The keywords used when searching these databases are also provided. Furthermore, Boolean operators were applied to expand and/or reduce the search results.

<i>Data Bases Searched</i>					
<i>PubMed</i>	<i>Medline via Ovid</i>	<i>AMED</i>	<i>CINAHL via EBSCO</i>	<i>ScienceDirect</i>	<i>Scopus</i>
Keywords Used	Family-centred care OR Family-centred care OR Family-centred practice OR Family-centered practice				
	Parents OR Carers OR mother OR father				
	Experiences OR Lived experiences OR perceptions				
	Children rehabilitation OR Child rehabilitation paediatric rehabilitation OR paediatric rehabilitation				
	Children physiotherapy OR children physical therapy OR child physiotherapy OR child physical therapy				
	Physiotherapists OR Physical therapists				
	Disability OR childhood disability				
	Children with disabilities OR child with disabilities OR children with special needs OR child with special needs				
	Saudi Arabia				

Table 1 Databases searched.

3.6 Inclusion and Exclusion Criteria for Articles

The literature search aimed to identify studies that addressed the literature review questions; hence, the inclusion and exclusion criteria for the articles are listed in Table 2 below. These criteria were established to ensure that all relevant literature related to the study area was covered.

Inclusion Criteria	Exclusion Criteria
FCC and paediatric rehabilitation/children rehabilitation (in Saudi Arabia and worldwide)	Conference papers
FCC in nursing, medicine or other healthcare professions (in Saudi only)	Posters presented at conferences
The experiences of either parents or healthcare workers of FCC in paediatric treatment or rehabilitation	Studies not written in English
FCC exploration using different methodologies (Quantitative, Qualitative, Mixed-Methods)	Studies exploring FCC in adulthood
Full-text articles	
Peer-reviewed papers	
PhD thesis within the Saudi context, FCC context, or rehabilitation context	

Table 2 Inclusion and exclusion criteria for articles

3.7 Quality Assessment of Studies

Twenty-five articles met the inclusion criteria. The selectivity of the papers was based on their relevance to the aim, objectives, and research question of this study. The Critical Appraisal Skills Programme (CASP) modified online version has been used to appraise the qualitative studies identified (Critical Appraisal Checklists) (Appendix N), which was initially developed by the University of Oxford's Public Health Research Unit. The appraisal tool included checklists tailored to each type of research design, including qualitative research. Additionally, the Critical Appraisal Checklist for Cross-Sectional Study (Survey) (Appendix O) was used to appraise the quantitative studies (Center for Evidence-Based Management (July 2014), Critical Appraisal Checklist for Cross-Sectional Study). Each paper included was read several times and was appraised using these tools. An overview of the articles screening process can be seen in the PRISMA diagram below.

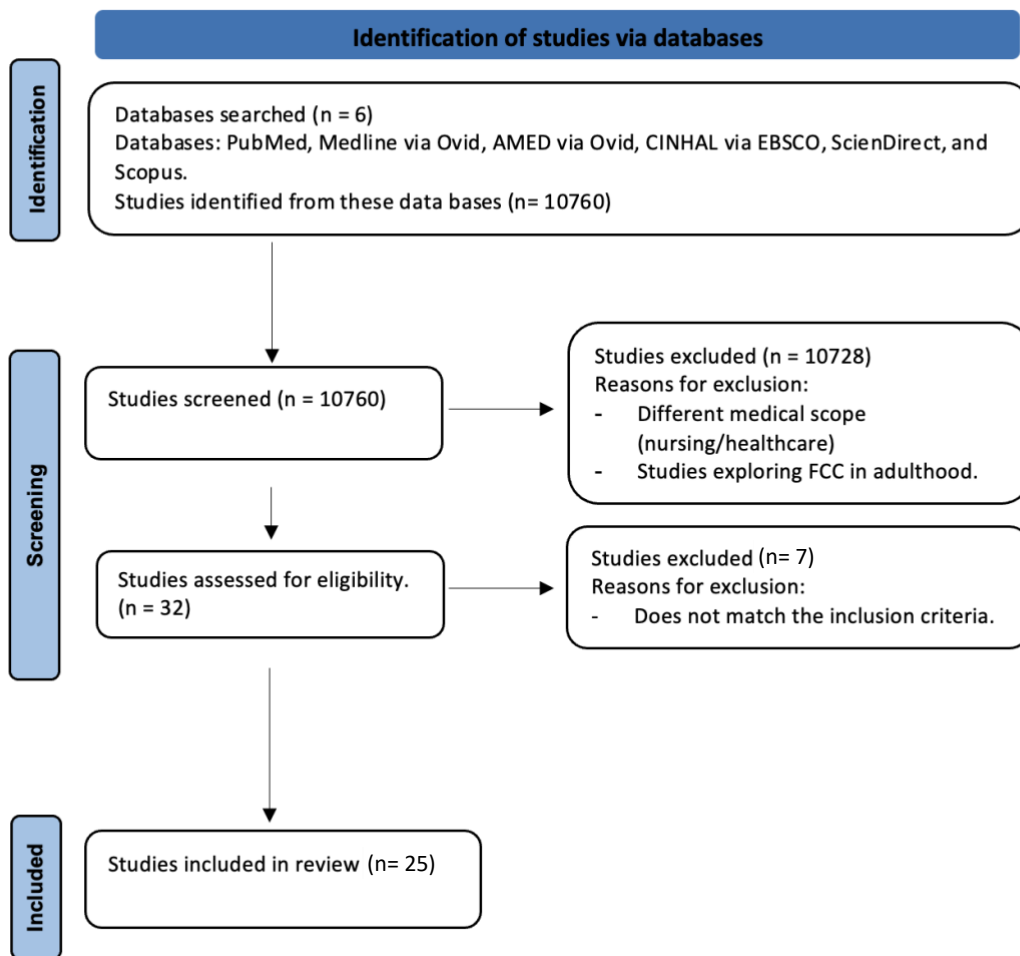


Figure 2 Articles screening process PRISMA Diagram

3.8 Study Characteristics

After searching the different databases, it was revealed that most of the articles and research exploring FCC within the scope of paediatric rehabilitation (Children's age range in these articles ranged between 0-18yrs). These articles used different methodologies. Four studies have used a qualitative approach (Morgan and Tan 2010; Ziegler et al. 2019; Argall et al. 2021; Poojari et al. 2021). Thirteen studies have used a quantitative approach (Garant et al. 2002; Saleh and Almasri 2013; Myrhaug et al. 2014; Sršen et al. 2014; Wang et al. 2014; Alnajjar and Elarousy 2017; Molinaro et al. 2017; Terwiel et al. 2017; Kang et al. 2017; Shevell et al. 2018; McManus et al. 2019; Antunes and Vaz 2021; Manzuma et al. 2021). These studies have used MPOC tools (MPOC-20/MPOC-56/MPOC-SP), which is a self-report questionnaire that measures parents' perceptions of how family-centred health services they and their child(ren) receive. Alternatively, MPOC-SP is meant to serve as a self-assessment tool for pediatric service professionals to assess their level of family-centredness practice (CanChild 2021). The questionnaires are set around five main domains to care, including 'Enabling and Partnership', 'Providing General Information', 'Providing Specific Information about the Child', 'Coordinated and Comprehensive Care for the Child and Family', and 'Respectful and Supportive Care' (CanChild 2021).

Seven studies have used a mixed-methods approach in which the MPOC-20/MPOC-56 for parents and MPOC-SP for staff questionnaires were used along with either semi-structured individual interviews or focus groups to expand more on the results of the quantitative part including (Dickens et al. 2010; Pickering and Busse 2010; Schreiber et al. 2011; Arnadottir and Egilson 2012; Arcuri et al. 2015; Stefansdottir et al. 2015); Alabdulaziz 2017).

Due to the heterogeneity in the contextual backgrounds of the identified studies, this review included studies conducted in different geographical locations. Nine of the studies were from European countries, one study was from the United Kingdom, three studies were from Asian countries, four studies were from North America, one study was from South America, three studies were from Australia, one study was from Africa, one was from Middle Eastern countries, and two studies were from Saudi Arabia. It is essential to recognise this variation to better

comprehend and interpret the findings of these studies, as well as their potential implications in different study settings. This provides a comprehensive understanding of the phenomenon under study. There is a clear gap in the literature regarding FCC and children’s rehabilitation, particularly in Saudi rehabilitation settings, which justifies the need for this study.

3.9 Family-Centred Care in the Wider Context

The following is a discussion of the existing literature on family-centred care, in which the FCC worldwide is explored first, followed by the exploration of FCC in Saudi Arabia. Each section is organised by the themes revealed in the studies explored, which are presented in the following table (table 3):

Key themes	Articles
Perceptions of family-centred care	<i>Dickens et al. (2010), Schreiber et. al (2011), Saleh and Almasri (2013), Stefansdottir et al. (2015), Arcuri et al. (2015), Alabdulaziz (2017), Alnajjar and Elarousy (2017), Molinaro et. al (2017)</i>
What affects the perception of FCC	<i>Garant et al. (2002), Saleh and Almasri (2013), Stefansdottir et al. (2015), Molinaro et. al (2017), Manzuma et al. (2021)</i>
Perceptions of disability and acceptance of a diagnosis	<i>Arcuri et al. (2015)</i>
Perceptions of roles of care	<i>Arnadottir and Egilson (2012), Stefansdottir et al. (2015), (Poojari et al. 2021)</i>
Respectful care	<i>Garant et al. (2002), Saleh and Almasri (2013), Myrhaug et al. (2014), Arcuri et al. (2015), Stefansdottir et al. (2015), Kang et al. (2017), Shevell et. al (2018), McManus et al. (2019), Molinaro et. al (2017), Antunes and Vaz (2021), Manzuma et al. (2021), (Poojari et al. 2021)</i>

<i>The importance of communication</i>	<i>Arnadottir and Egilson (2012), Ziegler et al. (2019), Argall et al. (2021), Manzuma et al. (2021), (Poojari et al. 2021)</i>
<i>Lack of information provision</i>	<i>Garant et al. (2002), Dickens et al. (2010), Pickering and Busse (2010), Morgan and Tan (2010), Schreiber et. al (2011), Arnadottir and Egilson (2012), Saleh and Almasri (2013), Myrhaug et al. (2014), Wang et al. (2014), Sršen et al. (2014), Stefansdottir et al. (2015), Molinaro et. al (2017), Kang et al. (2017), Alnajjar & Elarousy, (2017), Terwiel et. al (2017), Shevell et. al. (2018), McManus et al. (2019), Antunes and Vaz (2021), Manzuma et al. (2021), (Poojari et al. 2021)</i>
<i>Collaborative partnerships</i>	<i>Dickens et al. (2010), Morgan and Tan (2010), Schreiber et. al (2011), Sršen et al. (2014), Stefansdottir et al. (2015), Molinaro et. al (2017), Argall et al. (2021)</i>
<i>What parents value in family-centred Care</i>	<i>Morgan and Tan (2010), Schreiber et. al (2011), Arnadottir and Egilson (2012), Wang et al. (2014), Stefansdottir et al. (2015), Molinaro et. al (2017), Terwiel et. al (2017), Ziegler et al. 2019), Antunes and Vaz (2021), Argall et al. (2021)</i>
<i>Barriers to family-centred care</i>	<i>Arcuri et al. (2015), Alabdulaziz (2017)</i>

Table 3 Key themes from the literature review

3.9.1 Family-Centred Care Worldwide

3.9.1.1 Perceptions of family-centred care

The literature revealed few studies that examined parents' and healthcare professionals' understandings of family-centred care as a concept, including: Garant et al. (2002), Dickens et al. (2010), Schreiber et al. (2011), Saleh and Almasri (2013), Stefansdottir et al. (2015), Arcuri et al. (2015), Molinaro et al. (2017).

Dickens et al. (2010) revealed that family-centred care was generally understood and positively perceived by the parents in their study, which implies that the rehabilitation services were well coordinated and collaborative. In their study, Dickens et al. (2010) examined the perceptions of service providers and parents regarding FCC in rehabilitation services at a children's hospital in Australia using a mixed-methodology approach. The study aimed to compare metropolitan and non-metropolitan-based parents' perceptions of FCC and the perceptions of parents based on the number of physical disabilities of the child, using the Measure of Process of Care (MPOC-20). Additionally, the Measure of Process of Care for Service Providers (MPOC-SP) was used for healthcare workers' views and was followed by an open-ended question regarding the meaning of FCC. A total of 100 parents and 32 staff participated in this study, including staff from medical and non-medical professions.

Results from the interviews indicated that service providers had a good understanding of what family-centred care is, as these two main themes emerged: "the needs of the family, as well as the child, are considered throughout the rehabilitation process", and "treatment and decision-making partnerships are encouraged." Healthcare providers recognised the importance of partnerships with families when it came to treatment planning, decision-making, and service provision. Some limitations of the study, such as the small sample size and language barrier, were clearly identified. According to Puhan et al. (2012), the identification of study limitations is very important as it can help future researchers and readers to better evaluate the study's findings. However, the results may not truly reflect physiotherapists' perceptions as the study included a

diverse sample of participants from medical and non-medical backgrounds who may hold different perceptions and experiences compared to physiotherapists. In fact, Feeg et al. (2016) indicated that different healthcare providers have varying perceptions of working with children and parents, as they hold differing beliefs, which can challenge their understanding of the underlying principle that FCC is a philosophy, model, or system of care.

Schreiber et al. (2011) explored parents' perspectives on rehabilitation services provided to children with disabilities using a mixed-method approach in the USA. The MPOC-20 questionnaire was used to collect quantitative data, and interviews were conducted to collect qualitative data. A total of 711 questionnaires were mailed; however, only 249 were returned, implying a low response rate of 35%. A total of 130 families were contacted for an interview; however, only 11 participated in the interviews. Parents had a positive perception of the family-centred care that they were receiving from therapists, in which all domains of the MPOC-20 were rated to be happening to a fairly great extent, with the exception of the domain "providing general information." It is important to acknowledge that researchers conducted piloting, which provided them with an opportunity to reflect on and modify interview questions. In fact, the results of a pilot study allow researchers to better understand the challenges that might occur when the substantive study begins, and researchers will be more confident when using the instruments of data collection (Malmqvist et al. 2019). A disadvantage, however, was the lack of information provided about the interview, how and where it was conducted, whether it was a semi-structured or open-ended interview and whether participants were interviewed individually or in groups. Such information is important as it can reveal the different possible biases resulting from the use of various interview methods, such as social desirability bias (Andersen and Mayerl 2019).

Arcuri et al.'s (2015) study revealed an overall positive perception and satisfaction of FCC as reported by both parents and therapists. In their study, the perceptions of parents and healthcare staff regarding FCC in a paediatric rehabilitation setting were explored in Canada using a mixed-methodology approach. The MPOC-20 was distributed to 19 parents of children with physical disabilities aged 2-5 years, using a convenience sampling technique, however, only eight parents participated in the individual interviews. Additionally, seven healthcare providers (HCP) filled in the MPOC-SP questionnaire and participated in the focus groups and these studies indicate that

family-centred care was an understandable concept for different parents within these contexts of care.

3.9.1.2 What affects the perception of FCC?

The literature has shown that different factors affected parents' perceptions of family-centred care. According to Garant et al. (2002), there is a relationship between the child's type of disability and the parents' perception of family-centred care. In their quantitative research, Garant et al. (2002) evaluated rehabilitation services from the perspective of parents using the Swedish version of the MPOC-20. They concluded that several significant differences were observed in regard to age groups and disabilities. Parents of older children (7-18 years) felt that rehabilitation services offered to older children were less family-centred, whilst parents of younger children (0-6 years) felt that rehabilitation services offered to their children were more family-centric. Additionally, there were significant differences between disability groups. MPOC-28 scores were lower amongst parents of children with multiple disabilities than parents of children with a single disability. This might suggest the impact of a child's disability and age on parents' understanding and perceptions of FCC. However, in their discussion of MPOC questionnaire results, Garant et al. (2002) did not provide an explanation for the difference between results for parents of children of different ages, which would have led to more appropriate conclusions. Additionally, outcomes must be treated with caution as the study may be outdated since we are now in the year 2023.

In Jordan, Saleh and Almasri (2013) suggested that cultural differences may have an impact on the parents' perception of family-centred care. In their study, the healthcare services provided for children with CP and their families were assessed using the Arabic version of the MPOC-20 questionnaire. Saleh and Almasri (2013) were interested in examining the psychometric properties of the Arabic MPOC-20 to determine Jordanians' perceptions of FCC. In face-to-face interviews, the survey was administered along with an information sheet about the study, a self-report questionnaire to gather demographic information regarding both the child and the parent,

and a self-report questionnaire to determine whether the parents were satisfied with the rehabilitation services. With the use of convenience sampling, 114 parents from two major public hospitals and three private clinics were recruited, and almost all of the participants were mothers with a secondary education level raising CP children between the age of one month and seventeen years. Saleh and Almasri's (2013) study is similar to the Saudi context and attempts to provide insight into how Jordanian parents perceive FCC in rehabilitation settings. However, it does not provide an in-depth explanation of how culture influenced the perceptions of parents, which could have supported or strengthened their statement, as well as give a better understanding of the possible impact of culture on parents' perceptions of FCC.

Children's age, functional performance, and type of disability were highlighted as factors that influenced parents' experiences, according to Stefansdottir et al. (2015). The study examined the perception of parents and therapists regarding the family-centredness of rehabilitation services in Iceland using a mixed-method approach. The MPOC-32 and MPOC-SP were used, along with an open interview with parents, and a total of 236 parents and 25 health staff (physiotherapists and occupational therapists) were included in the study. However, only five parents participated in the interviews. The study showed that there was a significant difference between the domains' enabling and partnership,' 'providing specific information,' and 'coordinating and comprehensive care' between the two groups of children under investigation, children aged 0 to 11 and children aged 12 to 18. In agreement with Garant et al. (2002), the services were perceived as more family-centred by parents of younger children in all cases.

Additionally, significant differences were also found in parents' perceptions of therapy according to the child's functional performance. Parents of children who needed considerable assistance assessed 'enabling and partnership', 'providing specific information', and 'coordinated and comprehensive care' lower than parents of children who were fully independent. Furthermore, parents of children with physical disabilities were more satisfied with the general information they received, as well as coordination and understanding of care, than parents of children with autism and other disabilities. Based on these findings, it appears that the younger the children are and the less complicated their condition is, the more positive their parents' perception of family-centred care will be. Stefansdottir et al. (2015) have sufficiently and rigorously provided

the details of the study methodology, such as the participant recruitment process, the questionnaire distribution procedure, and information about participant confidentiality, which increases the generalisability of findings. However, the results must be treated with caution as the therapists in the study were recruited from one centre, which might not represent the perspective of other therapists working in a different setting (Gellman and Turner 2019).

In their observational study, Molinaro et al. (2017) discovered some associations between the perception of FCC and other sociodemographic characteristics as they explored family-centred care for children with CP in Italy. A total of 314 families and 290 healthcare providers were recruited for the study, in which they completed the Italian version of the MPOC-20 and MPOC-SP questionnaires and returned them by mail. A significant relationship was found between the MPOC scores and the variables related to the children's age. However, there was no association between the MPOC scores and other characteristics of the children, such as their sex or the severity of their illness. This finding contrasts with Garant et al. (2002) study, which revealed an association between MPOC scores and the severity of the disability. This suggests a need, however, to examine the cultural context in which both studies were conducted to help understand why these different relationships emerged.

Other associations were related to parents' characteristics, in which families with low socio-economic status, single parents or unemployed parents, and older mothers tended to report lower MPOC-20 scores. This suggests that different characteristics of parents affect their perceptions of family-centred care and what they expect from it in terms of what they think is important and what they do not. Although Molinaro et al. (2017) highlighted the associations and relationships between low MPOC scoring and families' socio-economic characteristics of parents and children, results must be treated with caution as the authors did not provide any clear information about their study limitations. Having Molinaro et al. (2017) acknowledge their study limitation increases the trustworthiness of findings, as it helps researchers recognise potential barriers to using clinical evidence (Puhan et al. 2012).

Similarly, Manzuma et al. (2021) revealed a negative association between the caregiver's level of education and the two MPOC-20 domains of 'enabling and partnership' and 'providing specific

information domain', indicating that the caregiver's perception of family-centred behaviours in these domains decreases as their educational level increases. In their cross-sectional study, Manzuma et al. (2021) explored the caregivers' and physiotherapists' perceptions regarding the extent to which family-centred care is implemented in pediatric physiotherapy services in Kano State, Nigeria. A total of 47 physiotherapists and 105 caregivers of children with CP aged 1-13 yrs old participated in this study using the MPOC-20 for caregivers and MPOC-SP for healthcare workers. Caregiver's age was found to have no significant relationship with any FCC domain; however, there was a negative relationship between the caregiver's education level and their perception of being partners in their children's care. This negative correlation indicates that caregivers with a higher level of education rated the physiotherapists' ability to create an enabling environment and view them as partners, possibly because they expected a higher level of collaboration than those with lower educational levels, who were completely satisfied with their level of involvement in their children's care.

3.9.1.3 Perceptions of disability and acceptance of a diagnosis

The literature reveals that parents' perceptions of their child's disability vary as they reflect on their experiences with accepting the disability and the challenges they face during this process. Arcuri et al. (2015) identified two themes related to this: 'parental perceptions of disability and acceptance of a diagnosis; parental acceptance of prognosis as an ongoing process involving various emotions' and 'the process in which the diagnosis is given'. These themes encompass the range of emotions parents experience concerning their child's condition, such as stress and sadness following the diagnosis. Moreover, parents reported feeling numbness as they moved beyond the initial pain and sadness, which formed part of the healing process. One parent noted that receiving a diagnosis provided clarity about the child's developmental delay because some parents were uncertain about their child's developmental trajectory prior to the diagnosis. Another parent expressed the need for support from medical staff to help guide them through the understanding and acceptance process.

Based on these findings, it is clear that the process of coping with the news of a child's disability varies amongst parents, as they experience different emotions and feelings related to raising a child with a disability. Additionally, parents perceive the process by which the diagnosis is given differently. Some reported that the language used during this process was confusing due to unfamiliar medical terms. Consequently, the presence of interpreters assisted some parents in better understanding the diagnostic information, particularly when language barriers were present, and was considered helpful. Many parents expressed that having healthcare staff explain their child's report was informative. In fact, some parents suggested that receiving a summary of their child's development would have been valuable and could have improved their understanding of the child's condition. This highlights the importance of addressing parents' information needs about their children's conditions in a simple and comprehensible manner.

3.9.1.4 Perceptions of roles of care

Arnadottir and Egilson (2012) found that parents felt healthcare professionals should encourage them to utilise their knowledge rather than unilaterally deciding the role they should play. The study explored the perspectives of Icelandic parents regarding rehabilitation services provided for their children with physical disabilities in two rehabilitation centres, using a mixed-methodology approach. The Icelandic version of MPOC-20 was employed, with an open-ended question added to the questionnaire, asking parents for their views on the healthcare services provided. After completing the MPOC-20, parents were invited to participate in a two-hour focus group. A purposeful sampling method was employed, with 96 parents of children aged 2-18 years agreeing to participate, and only six out of the 96 parents participating in the interviews.

The study suggested that parents' perceptions of their role in care were influenced by the attitude of healthcare workers, as some parents emphasised the importance of professionals acknowledging that parents know their children best. This recognition was found to be beneficial for those caring for their children with disabilities. This finding illustrates how parents hold different views of themselves as caregivers for their children and desire to have their perspectives

acknowledged. The study was robust overall, providing detailed information regarding the study methodology, participant recruitment, data collection procedures, the reliability and applicability of MPOC-20 within the Icelandic context, and areas requiring service improvement. However, the results, particularly the quantitative portion, represent only the Icelandic population studied and might not be generalisable to different populations, as diverse cultures may have varying perceptions and views (Gellman and Turner 2019).

Stefansdottir et al. (2015) highlighted the importance of understanding the parental role when attending sessions with their children with disabilities. Their study revealed that the parent's role in the intervention process was described as unclear when attending therapy sessions. One participant explained that healthcare workers did not provide sufficient encouragement regarding what parents should do or clarify their role in the treatment, resulting in parents adopting a passive role during the sessions. This finding suggests that discussing roles with parents is highly valued and crucial for families in FCC. However, Stefansdottir et al. (2015) did not elaborate on this point, which would have provided a clearer explanation of the findings.

In a similar vein, Poojari et al. (2021) notes that, despite the fact that parental participation in therapeutic processes enables them to develop a sense of competence about their role as active participants in their child's treatment, parents may not always be conscious of their roles as partners. In South India, Poojari et al. (2021) explored the perceptions of family-centred care among 14 caregivers of children with CP aged 4 to 12 years using qualitative methods, which included face-to-face interviews. The findings highlighted the significance of health service providers taking the initiative to explain the concept and relevance of FCC and parental role in child's care regularly. Although the study was informative, the results should be interpreted cautiously as Poojari et al. (2021) failed to report their study limitations. When researchers are aware of the limitations of a study, they can identify the various factors that may impede the application of clinical evidence (Puhan et al. 2012).

3.9.1.5 Respectful care

The importance of feeling valued and being treated with respect is reflected in previous literature exploring family-centred care. In Garant et al.'s (2002) study, parents considered being treated as individuals rather than just parents of a child with a disability to be essential when delivering FCC, which made them feel respected. Saleh and Almasri (2013) suggested that Jordanian parents might perceive service delivery differently due to cultural differences. Although parents gave higher scores for the 'respectful and supportive care' scale and subscales of 'treat you as an equal rather than just as the parent of a patient' and 'provide enough time to talk so you do not feel rushed', Saleh and Almasri (2013) implied that, within Jordanian culture, offering coordinated services such as providing consistent information and working with at least one healthcare worker over an extended period could be perceived as exhibiting respect for parents.

Myrhaug et al. (2014) found that parents valued receiving respectful and coordinated care, as the two domains of 'respectful and supportive care' and 'coordinated and comprehensive care' received the highest scores on the MPOC-20. The study documented the experiences of parents of preschoolers with CP in Norway to assess FCC in the primary healthcare system, including 121 parents who were mostly educated mothers with children aged six years old or younger. The authors suggested that service providers have a high degree of competence in relational helping to explain the findings. Moreover, the study discovered a correlation between parent satisfaction with the services provided and the experience of receiving respectful and supportive care. This was related to receiving financial and social support, along with more child-directed services, all of which contributed to parents feeling respected and supported. The results emphasise the importance of receiving appropriate support services that are delivered respectfully and meet the unique needs of each family within the context of FCC. However, the study by Myrhaug et al. (2014) should be interpreted with caution due to its limitations. The authors recognised low response rates and limited sample size as constraints. Although postal surveys typically have low response rates, this drawback might have impacted the results, leading to a non-response bias of 66%. A small sample may not accurately represent the population, affecting the validity and reliability of survey results (Fincham 2008; Colin and McCartan 2016).

Similarly, Arcuri et al. (2015) found that parents and healthcare providers considered the provision of respectful and supportive care to be a crucial aspect of rehabilitation services, as it received the highest score on the MPOC scale. Interview outcomes revealed the theme of 'the manner in which parents are treated by the HCP', reflecting parents' experiences of feeling respected and supported through sincere interactions between them and their children's healthcare staff. Additionally, when parents were given sufficient time to ask questions without feeling rushed, they felt respected and supported, as they were involved in the process, and their questions and concerns were addressed.

In Stefansdottir et al.'s (2015) study, parents expressed how respect and mutual trust were the two most valuable elements of rehabilitation services that they received from professionals. Indeed, one mother described how her child's occupational therapist was always interested and took the time to speak with her, even when they were just passing by, which made her feel valued.

In Kang et al.'s (2017) study, treating people with respect was perceived as important, as the highest rating was given to the domain of 'treating people respectfully'. The study examined healthcare professionals' perceptions of family-centred care for early intervention (EI) treatment in Taiwan in relation to their years of experience and type of profession. The Chinese C-MPOC-SP questionnaire was used, and a convenience sample of 94 healthcare staff with at least one year of experience participated. The sample was collected from five different EI programmes in Taiwan using a snowball method, and participants came from various medical disciplines, including physiotherapists, occupational therapists, speech-language pathologists, social workers, and childhood educators.

The results indicated a strong association between healthcare workers' years of experience and their demonstration of FCC practices, as workers with more experience demonstrated FCC behaviours in all four scales of the C-MPOC-SP. More specifically, years of experience in EI were correlated with higher perceptions of displaying sensitivity and respect to parents. This suggests that years of experience and working with families have influenced the way healthcare workers behave towards families within the context of family-centred care. The use of snowballing was a

limitation of the study, as the sample includes only individuals who work in EI settings and not all settings (Gellman and Turner 2019). This approach involves identifying participants using the 'snowballing' technique, in which recognised individuals are asked to propose more applicants who may match the criteria. This method is particularly beneficial when access to the investigated population is challenging (Parker et al. 2019). Despite this limitation, a positive aspect to acknowledge was the authors testing the reliability and internal consistency of the C-MPOC-SP questionnaire, which reflects the accurate measurement of variables being studied and thereby influences the reproducibility and generalisability of study outcomes (Lobiondo-Wood and Haber 2014).

Molinaro et al. (2017) found that both parents and healthcare workers perceived the highest ratings on the MPOC-20 questionnaires to be related to the domains of 'coordination and comprehensive care' and 'respectful and supportive care'. The MPOC-SP revealed that the highest rating was for the domain of 'treating people respectfully', suggesting that parents felt respected to a satisfactory degree and that healthcare workers treated parents respectfully.

Similarly, in the study of Shevell et al. (2018), parents rated the MPOC-56 domain of 'respectful and supportive care' the highest, reflecting its importance. Shevell et al. (2018) investigated parents' perceptions of family-centred care for children with CP in Canada using the MPOC-56 questionnaire to relate the parents' perceptions to the socio-economic status of families. A total of 282 parents of children participated in the study from four different regions, and the results reflected the centredness of care received. A limitation to this study was that the authors did not provide a clear explanation for their results or observations, which can make it difficult for another researcher to interpret these findings in the broader context of family-centred care. This can lead to interpretation bias, where researchers report only favourable results and interpretations from their study, leading to serious misconduct (Šimundić 2013).

In McManus et al.'s (2019) study, receiving a more intensive treatment was found to positively influence parents' perceptions of receiving more respectful care. In their cross-sectional study, McManus et al. (2019) explored the parent's and service providers' perceptions of family-centred care in EI clinical setting using a quantitative approach. The research included 29 parents of

children receiving EI services and 12 service providers with at least one year of experience in EI. The Measurement Process of Care questionnaire for both families and staff were used (MPOC-56; MPOC-SP). It was found that caregivers and healthcare providers perceived high levels of involvement in FCC structures in EI care, as respectful and supportive care was perceived to be happening by both parents and healthcare workers. The study showed that parents were more likely to feel respected if they received more intensive services, and a greater level of service intensity could enable providers and families to build trust and provide support and care. This illustrates the significance of having intensive services that meet the needs of families and their desires. However, the generalisability of this study might be questioned, as the sample may not represent the perspectives of other parents and healthcare workers working in other clinical settings but only reflect the perceptions of the pre-determined population included (Gellman and Turner 2019).

In Antunes and Vaz's (2021) study, parents expressed how having their opinions heard by the staff was an essential aspect of care that ensured the provision of good quality services and met their needs and expectations. The study examined family-centred care for the rehabilitation of children with physical disabilities in Brazil to explore parents' and healthcare workers' perceptions of FCC. A total of 107 parents and 89 service providers participated in the study, and data were collected using the Brazilian MPOC-20 and MPOC-SP questionnaires. The healthcare staff filled out the self-administrated questionnaire by themselves, whilst the parents filled it out orally over the phone as a researcher called them and filled it out for them.

The results from the MPOC-20 revealed that parents rated the domain of 'enabling and partnership' the highest, followed by 'coordinated and comprehensive care' and 'supportive care', whilst staff have rated the domains of 'treating people with respect' the highest. Reflecting a positive perception towards the care given or received. Despite how much collaboration between the healthcare workers and parents and sharing the rehabilitation goals meant to them both, it was not a practice that is being implemented in the Brazilian rehabilitation setting frequently, as Antunes and Vaz (2021) declared, suggesting a gap in clinical practice. No further explanation was provided by Antunes and Vaz (2021), which could help better understand these findings.

The study by Antunes and Vaz (2021) contributes to the body of knowledge regarding FCC in a Brazilian rehabilitation setting; however, it does have some limitations. The high scores of Antunes and Vaz's (2021) study must be treated with caution, as these may be influenced by the fact that participants, especially parents, gave answers that might not represent their true perceptions since interviews were conducted over the phone. A social desirability response bias may have occurred, as some parents may have provided false responses intended to portray a positive image of themselves in order not to affect their children's treatment at the facility (Colin and McCartan 2016; Andersen and Mayerl 2019). Another issue is that Antunes and Vaz's (2021) study was conducted in a specific rehabilitation centre that incorporated the elements of FCC into practice, and therefore, the results might not represent the perceptions of other parents and therapists in different clinical settings (Gellman and Turner 2019).

In Manzuma et al.'s study (2021), mutual respect was reflected in the results of both parents and physiotherapists. 71.4% of the parents in this study reported that pediatric physiotherapists were very respectful and supportive, and the domain of 'respectful and supportive care' had the highest score ratings. On the other hand, 53.2% of the physiotherapists reported treating the caregivers and children with a high degree of respect. This was related to the healthcare staff's attitude toward the parents, in which they made the parents feel competent, which was perceived as a form of respect.

Poojari et al. (2021) found that parents felt respected during their child's treatment; however, they preferred to be questioned about their health status before being criticised for failing to perform the recommended home exercise program. Additionally, the mothers had an ongoing requirement for direction and assistance from the beginning to deal with life's difficulties and offer better care for their children.

The above studies suggest that parents can feel respected and supported for various reasons. However, they all conclude that receiving respectful care that meets a parent's desires and needs and is delivered in a respectful manner is of paramount importance within the context of family-centred care.

3.9.1.6 The importance of communication

Communication between the parents of children with disabilities and various healthcare workers is crucial for effective care (Reber et al. 2012). However, only a limited number of articles identified communication as a theme. Manzuma et al.'s study (2021) concluded that parents perceived having enough time to communicate their concerns, particularly during their initial visit made them feel satisfied with the rehabilitation services provided. Additionally, Poojari et al. (2021) implied that caregivers are more able to comprehend their own roles as well as the roles of healthcare providers when there is open communication between all parties involved.

Indeed, honest and open communication between parents and clinicians was found to be helpful in building rapport between them (Argall et al. 2021). In their qualitative study, Argall et al. (2021) explored parental perceptions of the family-centred model of care integrated into a public child developmental service. Employing a descriptive interpretative phenomenological approach, 22 parents/caregivers were recruited to the study using convenience sampling. Semi-structured face-to-face and phone interviews were conducted, and data were analysed by three investigators using open coding and a deductive approach in which data were coded axially. Of the 22 participants initially approached, only 15 participated in the study.

'Communication' emerged as a prominent theme from the findings, reflecting how the quality of communication, whether positive or negative, directly influenced parents' experiences with their child's care. Effective communication is considered essential for parents to help them understand their child's assessment processes, developmental profiles, and future healthcare journeys. Moreover, parents expressed the importance of being able to ask questions and express concerns as part of the communication between them and healthcare workers treating their children, a factor they highly valued. This highlights the significance of having the opportunity to be heard.

Despite the above, Argall et al.'s (2021) study contributes to the body of knowledge on family-centred care by exploring the model of care, which incorporates FCC and various tools such as the family goal-setting tool to support children with complex developmental problems, the results should be treated with caution. Firstly, whilst Argall et al. (2021) have explained how the

data were collected and analysed, thus reflecting the credibility of the study findings, the exact methodology followed was unclear. Argall et al. (2021) claimed that the data were analysed using open coding, suggesting that grounded theory was employed; however, the data were also analysed deductively, which contradicts the purpose of grounded theory. Secondly, the sample included parents who were being offered Child Development Services (CDS), which does not represent the experiences of parents receiving services at other centres. Furthermore, whilst Argall et al.'s (2021) study emphasised the importance of maintaining good communication between parents and healthcare workers, there is an evident lack of communication within the context of FCC, as reported by the following studies.

In the study by Arnadottir and Egilson (2012), parents desired better communication between their child's school and therapists, and the theme of 'communication and respect' emerged, reflecting this desire. Similarly, in the study by Ziegler et al. (2019), mothers valued communication between themselves and healthcare workers. These findings suggest a consistent need for families to have open communication channels with their children's healthcare workers. Ziegler et al. (2019) explored parents' experiences of family-centred care integrated into a new paediatric EI programme (COPCA) in Switzerland using a qualitative approach. As part of the Coping with and caring for infants with special needs (COPCA) approach, parent coaching is an important component of the solution-focused approach that facilitates the active participation of the infant (Hutchon et al. 2019). By adopting the coaching role, the physiotherapist contributes to the patient's self-management by assisting the patient in changing their behaviour while amplifying and strengthening their own inherent motivation during communication (Kortleve 2021). In this role, the physiotherapists guide patients in a way that allows them to retain control to achieve behavioural changes (e.g. regular exercise) and assist the patient in exploring their uncertainty towards change and reduce it to improve the intended outcomes (Kortleve 2021).

Ziegler et al. (2019) conducted a study which included 15 families who completed a questionnaire containing three open-ended questions to reflect on their experiences with the care provided. Outcomes revealed various aspects of care that mothers valued, including communication, which involved discussing concerns and receiving answers to questions. However, it appears that Ziegler

et al. (2019) did not elaborate or provide further information on this point in the article, which would have been beneficial in helping readers understand the implications of effective communication.

3.9.1.7 Lack of information provision

The majority of studies examining family-centred care have revealed an insufficient level of information sharing between parents and healthcare workers. The results from the studies indicate that the level of information provided was lacking and reveal the different associations between parents' perception of information and their sociodemographic characteristics, the various barriers to information provision and the parent's expectations of the approach and type of information they would like to receive and have access to.

The lack of information provided without parents specifically asking for it, not providing general information about the other resources available in the community and not knowing what alternative treatments are available are all considered a weakness in services by parents (Garant et al. 2002). Similarly, Dickens et al. (2010) indicated that the failure to provide general information about the types of services available in the community, information in multiple forms and information about the child's future outlook as well as not allowing family members to obtain information and not providing information about reaching out to other parents of children with disabilities were all identified as deficiencies in rehabilitation services. In the researchers' hypothesis, service providers sometimes do not have the time and resources to provide general information to parents due to the nature of the interaction between themselves and parents. This indicates that parents' various needs for different information are not being met and is a shortcoming in child rehabilitative care, exacerbated by other factors, such as a lack of time.

Pickering and Busse (2010) highlighted the difficulty parents experienced in finding accurate information. Parents found the written information provided by healthcare workers helpful, but it occasionally contained medical jargon that they struggled to understand, and sometimes access to information was restricted or unavailable. This lack of information hindered parents

from making informed decisions about their child's rehabilitation, even though they felt confident and in control, emphasising the importance of how information is presented and delivered.

Morgan and Tan (2010) reported that parents highly valued the information provided to them in family-centred care; however, only a few received information about their child, with parents of children with severe disabilities being the least likely to report receiving such information. The study investigated parents' perceptions of family-centred care for the rehabilitation of children with CP in Australia. A convenience sample of 24 parents participated in in-depth semi-structured individual interviews and small group interviews. The authors suggested that staff may be hesitant to deliver bad news or may lack the skills and resources to fully explain disability concepts. Nevertheless, most parents expressed a desire to understand the nature of their child's disability, the reasons for their child's treatment, and more information about various issues, including educational inclusion and future care possibilities for their child, similar to findings reported by Dickens et al. (2010).

Similarly, Schreiber et al. (2011) revealed the parental need for written information about their child as the theme of 'desire for additional written information' emerged from the qualitative data. There was a noticeable lack of information provided to parents regarding the child's disability, treatment, future outlook and expectations, and guidance on connecting with other parents of children with disabilities. Several parents expressed a desire for information to be provided more frequently, whilst others preferred information related to the child's progress and decisions about terminating or resuming services for the child, reflecting the diverse informational needs of parents of children with disabilities.

Arnadottir and Egilson (2012) reported that parents experienced a lack of information about service options, written information about their children's therapy activities, and information about their children's progress. Their study revealed a correlation between the child's disability, residence, and the level of information provided. Notably, parents of children with CP perceived services as more family-centred than those of children with myelomeningocele and neuromuscular conditions. Although these conditions may be less well-known due to fewer

affected children, parents may require additional information and support as neuromuscular disorders are often variable. Furthermore, parents living in the capital area reported significantly higher scores on the 'providing specific information' scale than those living in other areas. The study concluded that in small towns where parents and therapists live in close proximity, information is often shared orally rather than in writing, unlike in larger metropolitan areas. This demonstrates that parents' perceptions of the information they receive from healthcare workers are influenced by their child's medical condition and geographical location.

The literature reflects various associations between the sociodemographic characteristics of parents and children and their perceptions of and satisfaction with information provision. Stefansdottir et al. (2015) found a relationship between the child's disability and parental satisfaction with information provision. Families of children with physical disabilities were more satisfied with the information they received than those with children who have autism or other disabilities. In this study, parents perceived the provision of general information to be lacking in the service. According to the families, this may have limited their ability to seek vital support and make informed decisions about the service.

Similarly, Kang et al. (2017) revealed an association between healthcare providers' years of experience, type of profession, and their perception of the information provided. Kang et al. (2017) demonstrated that the domain of 'providing general information' was rated the lowest by healthcare staff, particularly by social workers and educators, in comparison to physiotherapists and occupational therapists. It was suggested that a clinical professional conducting a functional assessment and treatment might possess a more accurate perception of their ability to provide information specific to a child's condition and services than a social worker or an educator. Additionally, those with more extensive experience in EI were perceived to exhibit greater sensitivity and provide more detailed information about the child. However, this is not deemed to be a primary determinant of family-centred practice.

In the Netherlands, Terwiel et al. (2017) identified a correlation between the child's age and the importance ratings of the five domains of the MPOC-56. Terwiel et al. (2017) examined family-centred care for the rehabilitation of children with CP to uncover what parents of children with

disabilities consider important. A total of 175 parents participated in the study, completing the MPOC-56 questionnaire. The association revealed by Terwiel et al. (2017) concluded that when the child is younger, parents place greater importance on family-to-family interaction, and a lower educational level is associated with higher importance ratings for general information and for informing the entire family. Indeed, the provision of general information was considered highly important to parents, as they appreciated therapists giving them information about their child's activities during a session and the results of their assessment.

In a study by Shevell et al. (2018), parents ranked the provision of general information the lowest on the MPOC-56 questionnaire, reflecting its lesser importance to parents. Findings indicated that some MPOC-56 subscale scores were associated with specific sociodemographic characteristics of families of CP children. In particular, higher socio-economic status, as measured by either paternal academic achievement or household income, was significantly associated with a lower median score on either the 'Providing General Information' or 'Providing Specific Information' about the child subscale. In essence, this suggests that parents with higher socioeconomic status expect more from healthcare professionals, which contrasts with the findings of Terwiel et al. (2017). According to the authors, improvements can be made primarily in the general information provided and in meeting the expectations of families with high social status through the use of websites, other online resources, and assembled printed materials.

In Jordan, Saleh and Almasri (2013) reported a lack of information provided in rehabilitation settings, as parents rated the MPOC-20 domains of 'having information available to you in various forms, such as a booklet, kit, or video' and 'providing advice on how to get information or contact other parents' the lowest. Additionally, parents distinguished between providing general information and providing written information, reporting that the latter was lacking. This suggests that providing written information is not commonly practised in the Jordanian healthcare system, thus creating a barrier to FCC provision, as identified by the authors.

In Norway, 72-84% of parents reported a lack of information provided to them regarding their child's rehabilitation and identified this area of care as needing improvement in Myrhaug et al.'s (2014) study. This included information about the child's disability, the types of services available,

who received information and how it was provided, as well as information about how the family could contact another family experiencing similar circumstances. According to the findings, families of young children with CP require more information than they currently receive concerning diagnosis, intervention, and subsequent care for this condition, as well as how to get in touch with other families in similar situations. This contrasts with Arnadottir and Egilson's (2012) study, as both studies were conducted in different contexts, this might suggest that the cultural context of the study has an impact on the discovery of these associations.

In Myrhaug et al.'s (2014) study, many parents reported not receiving a full explanation of their child's treatment and felt that this information would enable them to make informed decisions regarding their child. Indeed, a person's capacity to participate effectively in decision-making is heavily dependent on having access to reliable information about diagnosis, treatment, and prognosis (McHugh et al. 2013). To facilitate families' access to reliable information, the authors suggested the use of various methods, including websites, leaflets, and parental education.

Wang et al. (2014) demonstrated that professionals' ability to deliver both general and specific information to parents of children with disabilities was inadequate. The researchers examined the perspectives of Chinese parents regarding FCC provided to their children with CP in rehabilitation settings. Parents of children with CP aged eight and younger were asked to complete the Chinese version of the MPOC-20 to assess the quality of rehabilitation services in outpatient rehabilitation centres and paediatric hospitals. A total of 205 parents were surveyed, with the majority being mothers holding a high school diploma or higher education level, resulting in a response rate of 86%. Based on the MPOC-20 survey results, the parents assigned the lowest rating to the domain 'providing general information' and identified it as a weak point in the services provided. This included details on the child's condition, their progress, the implications of the disability in the future, and written information regarding the child's treatment, suggesting the impact of receiving different information about the child. It was concluded that good coordination and collaboration would facilitate the sharing of information between family members and health professionals.

There are several advantages to the report. A positive aspect is that the researchers assessed the reliability and validity of the MPOC-20 amongst the Chinese population to test its applicability. The validity and reliability of an instrument are crucial, as they indicate whether its attributes are being measured accurately and consistently, thus influencing the reproducibility and generalisability of study outcomes (Lobiondo-Wood and Haber 2014). Furthermore, the study was sufficiently comprehensive, detailing the data collection process, ethical considerations, and the study's limitations and strengths. However, it is essential to interpret the results of Wang et al.'s (2014) study cautiously, as some barriers may have influenced the outcomes. Wang et al. (2014) did not provide a description of how the survey questionnaires were administered, which implies insufficient rigour in the data collection process (Kelly et al. 2003). In this instance, biases (such as interviewer bias and social desirability response bias) might be present if a face-to-face interview survey was employed (Colin and McCartan 2016; Andersen and Mayerl 2019).

A similar lack of information provided was evident in the study by Sršen et al. (2014). The Slovene parents' perceptions of the family-centredness of rehabilitation services for their children with disabilities were examined by Sršen et al. (2014). The MPOC-20 Slovene version, in conjunction with a client satisfaction questionnaire (CDQ-8) measuring parental satisfaction, was sent by post to parents of children with disabilities under 16 years. Of the 450 parents, 228 participated, the majority of whom were mothers and their children received services at various university hospitals, general hospitals, rehabilitation centres, and community health centres, yielding a response rate of 52%. In some institutions, parents received a complete written report upon discharge and were able to meet and obtain information from all team members, as well as discuss treatment options and rehabilitation programs with them. However, this was not always the case in other institutions that participated in the study. In fact, parent responses suggested that providing general information and specific information in a variety of formats, including brochures, is an area of the services parents feel needs improvement, as approximately one-fourth of the parents received information about the types of services in a limited or less frequent manner. According to parents, only 18% reported having access to information regarding their child's disability, and the same percentage reported having access to information for their entire family.

Additionally, parents were most dissatisfied with the availability of information in different formats and with the advice provided on how to get information or contact other parents. This led parents to seek information from the internet, the paediatrician, or from other parents. Furthermore, 20% of the parents were not satisfied with the availability of written material about what their child was doing in therapy. It was explained how written information on several specific disorders is not always available, particularly not in the Slovene language. This suggests that having access to reliable information, which all family members can access, is highly valued in the context of the FCC. Nonetheless, the predetermined schedule during a visit to a paediatric hospital and time limitations seem to hinder the healthcare worker's ability to accommodate the unique information needs of each parent, which aligns with the findings of Dickens et al. (2010).

Sršen et al. (2014) explain why Slovenia had comparatively high MPOC-20 ratings by citing its well-developed healthcare system, which takes a multidisciplinary approach and encourages physician-patient interaction. The authors state that this approach provides the therapist with more flexibility when responding to parent inquiries and promotes better access to information. An additional positive feature of the study is the transparency with which it disclosed study limitations, such as the low response rate, that could have impacted its results. Indeed, small sample sizes and low response rates may lead to a non-response bias, which may adversely affect the reliability and validity of the survey results (Fincham 2008). Despite this, by recognising the study limitations, researchers can identify the various factors that may impede the use of clinical evidence (Puhan et al. 2012). Although the study methodology was clear, it would have been more reader-friendly if the authors had presented the method of delivering the questionnaire and the response rate in the methodology and results section rather than the discussion section.

In Italy, cultural difference was the attributing factor to the lack of information provided to parents of children with disabilities, according to Molinaro et al. (2017). The study findings revealed that both parents and healthcare providers perceived the provision of general information as an area needing improvement, as both rated it the lowest in comparison to the other domains of the MPOC-20. Molinaro et al. (2017) point out how the issue with information might be related to cultural differences, as Italians have limited family links with other CP children's families, forcing parents to rely more on healthcare providers to get information about

the child rather than seeking information from other resources. This confirms the earlier suggestion that cultural factors may influence the way in which parents perceive the information they receive.

Similarly, both parents and healthcare workers perceived the domain of 'providing general information' as needing improvement, as both groups rated it the lowest (McManus et al. 2019). Interestingly, the authors discovered an inverse correlation between caregiver-reported specific information and service provider-reported general information. Specifically, higher information related to the child's condition was associated with decreases in general information from service providers. Despite this, general information was considered a crucial aspect of care. It helps parents better understand how to participate in family-to-family support groups, find resources to cope with the impact of their child's diagnosis, and identify external services and resources to assist them (McManus et al. 2019).

In a more recent study by Antunes and Vaz (2021), both parents and healthcare workers perceived the domains related to the provision of general and specific information as the lowest. This is consistent with the findings of Manzuma et al. 2021, which indicated that the majority of caregivers viewed the provision of specific and general information as insufficient. Parents reported not receiving written information regarding their child's therapy, progress, or assessment results. In addition, insufficient information was provided about the organisation's available services and the means by which the entire family can obtain information from various sources, such as libraries, pamphlets, videos, and other forms of familial support. There was an inverse relationship between parental level of education and information provision, with caregivers with lower levels of education perceiving they received a greater amount of specific information about their child's health. These studies suggest a need for improvement in services concerning the provision of written information and information on the child's treatment.

Similarly, Poojari et al. (2021) revealed that the provision of both specific and general information was of the utmost importance for caregivers. Although the information on the child's condition and progress were verbally communicated and documented in the file, some caregivers were unable to directly access the information and requested the progress report. Consequently, this

reflects the inadequate amount of information that was provided by healthcare workers, which did not meet the parental desires.

It can be inferred from the studies above that the lack of information provided to families remains an ongoing concern raised by numerous studies, reflecting a deficiency in the services provided that requires further research.

3.9.1.8 Collaborative Partnerships

Collaborative partnerships emerged from the literature and were viewed as a two-way process requiring acceptance from both parties, the families and the healthcare workers treating the child with a disability. Dickens et al. (2010) emphasised the importance of partnership with families, as the theme 'treatment and decision-making partnerships are encouraged' emerged from their qualitative data. This illustrates the service providers' recognition of the need to make decisions, plan treatment, and provide services in conjunction with the families when it comes to rehabilitation. Similarly, parents in the study by Schreiber et al. (2011) highlighted the importance of maintaining a personal and consistent relationship and collaboration between them and their child's therapist. Moreover, collaboration was one of the essential characteristics related to the parent-therapist relationship, reflecting parents' satisfaction. Furthermore, Sršen et al. (2014) attributed the high scores in their study for the domain of 'coordination and comprehensive care' to parents' satisfaction with services. This was due to the effective organisation of services within these institutions, where parents were invited to regular meetings with healthcare workers to discuss their children's functional abilities, set goals, and plan a programme together.

Although the collaboration and partnership between healthcare workers and parents are valued and accepted by parents, Morgan and Tan (2010) revealed that the severity of a child's disability can sometimes determine a family's desires and expectations from this partnership. Parents of children with mild disabilities were more likely to feel that they were experts on their child and expressed a desire to work closely with staff, suggesting the impact of the presumptive role of

care held by parents themselves on their level of engagement in their children's care. Most respondents felt that they should participate in the analysis, evaluation, and planning of the child's rehabilitation, including selecting rehabilitation goals, with the assistance of the staff. On the other hand, parents of children with severe disabilities preferred the staff to make decisions and implement treatment rather than attempting to manage their children's complex needs themselves. In most cases, parents of children with severe disabilities have lost hope in the collaborative process of setting goals and in rehabilitation after their child has not met the goals, they had set.

The results from Stefansdottir et al. (2015) reflected families' diverse perceptions and expectations for services, including their need for collaboration, which was related to the child's disability. Unlike the study of Morgan and Tan (2010), Stefansdottir et al. (2015) reported that families whose children require assistance at all times are more likely to perceive services and collaboration as family-oriented than families whose children require considerable assistance. Researchers explained that perhaps children with the most severe disabilities received more extensive services than those with less severe disabilities. Indeed, Molinaro et al. (2017) concluded that for children with long-term disabilities, such as CP, who require constant care, treating them over the long term promotes a healthier relationship between the child's parents and healthcare providers. Despite this, sharing goals resulted in effective collaboration between family members and therapists, leading to better intervention outcomes (Stefansdottir et al. 2015). Additionally, Argall et al. (2021) defined the development of a partnership between families and clinicians as an essential requirement for the successful application of family-centred care in clinical settings. This illustrates how a child's medical condition impacts parents' perceived collaboration and partnership, which can adversely affect the child's development and relationships between healthcare workers and families.

3.9.1.9 What parents value in family-centred care

Parents of children with disabilities receiving treatment in various clinical settings and from a variety of healthcare professionals highlighted several aspects of care that they deemed crucial. A few studies emphasised the importance of having their children treated by a constant therapist for an extended period of time rather than rotating between therapists. Parents in the study of Arnadottir and Egilson (2012) preferred having a key worker who worked closely with children and could provide all the necessary information about the child's condition. Likewise, parents appreciated having a constant therapist working with the child for a prolonged period, as this seemed to help develop a friendlier relationship between the therapists and parents (Molinaro et al. 2017).

Having a safe space to express their concerns and worries freely and obtain information was another essential aspect of rehabilitation services that parents greatly valued, as highlighted in the literature by several studies. Morgan and Tan (2010) indicated that, despite being treated with respect, some parents felt they were being questioned by staff but could not question the therapists in return, wishing for a free space to express their concerns for the future. Similarly, Terwiel et al. (2017) emphasised the importance of parents having their questions answered, having the opportunity to express concerns and opinions, and being fully informed about the different options for treatment and services available. Likewise, as discussed by Argall et al. (2021), parents perceived the ability to ask questions and have their concerns heard by the healthcare workers treating their children as an integral part of the communication between them, which they deeply valued. Despite this, giving parents enough time to ask questions and addressing the child's mental, social, and physical needs as a whole were identified as areas of weakness in the services provided (Wang et al. 2014), highlighting the significance of being heard and listened to by healthcare workers providing services to children with disabilities.

Similarly, Antunes and Vaz (2021) noted that although parents valued having their opinions heard by staff and considered it an essential aspect of care that ensured the delivery of high-quality services meeting their needs and expectations, healthcare providers did not always comply.

Further exploration is needed to identify the reasons behind such findings and possible barriers to the provision of such services for families of children with disabilities. Therapists showing care, devotion, and enthusiasm were highly valued by parents, as the personal characteristics and traits of each therapist were revealed to have an impact on the parents' experiences with rehabilitation services (Stefansdottir et al. 2015).

The parents' constant need for different types of support was another crucial aspect of family-centred care revealed in some studies. According to Argall et al. (2021), supporting families in finding hope and strength for their children was described by multiple families as a key factor emerging from good therapeutic connections and relationships and held great importance for them. Being supported by the child's therapist regarding the child's care provided mothers with a sense of competence and increased confidence in undertaking the child's rehabilitation, as they felt confirmed and reassured by the child's therapist (Ziegler et al. 2019).

Schreiber et al. (2011) revealed a theme called the 'desire for opportunities to connect and interact with other parents in similar circumstances'. In fact, the ability to interact with other parents in similar circumstances greatly benefited parents and was considered a coping mechanism (Schreiber et al. 2011). There was a strong desire for information regarding issues such as insurance and financial concerns, community resources, and adaptive equipment, as well as the notion of sharing the experience of raising a child with special needs (Schreiber et al. 2011). This suggests that different families have various and diverse needs, all of which must be respected and addressed within the context of family-centred care provision.

3.9.1.10 Barriers to family-centred care

Arcuri et al. (2015) have identified various barriers to the implementation of FCC in different clinical settings. In their study, Arcuri et al. (2015) reported that healthcare providers identified limited time and lack of resources as the two main barriers to providing FCC. The healthcare providers were overwhelmed by their workload, which limited their time and ability to provide effective FCC. This finding is consistent with the studies of Sršen et al. (2014) and Dickens et al.

(2010), which have highlighted the persistent problem healthcare workers have with time, affecting their ability to provide FCC effectively.

3.9.2 Family-Centred Care within the Saudi Context

The following section presents the different themes derived from the studies conducted in Saudi Arabia around the context of family-centred care, which led to four main themes.

3.9.2.1 Perceptions of family-centred care

In Saudi Arabia, the concept of family-centred care seemed to be an understandable concept, as revealed in the study by Alabdulaziz (2017). In their mixed-method study, Alabdulaziz (2017) examined the perceptions and practices of FCC in Saudi hospitals from the nurse's perspective. The results indicated that although the FCC concept was accepted within the Saudi context, it was not entirely adopted by the nurses, as they lacked the appropriate understanding of its meaning, resulting in irregular application in their practice. Similarly, Alnajjar and Elarousy (2017) revealed a general understanding of the concept of FCC among healthcare staff in Saudi Arabia, but it was not always implemented in practice. The authors explored the perceptions of doctors, nurses, and families regarding family needs in neonatal and paediatric intensive care units (PICU) in Saudi Arabia, with the aim of improving FCC to meet parents' expectations. A self-report questionnaire was used, including questions about the participants' demographics and a needs inventory related to support, information exchange, proximity, assurance, and comfort. The outcomes revealed that although healthcare staff had a good understanding of FCC, patients lacked an understanding of this concept. This indicates that family-centred care was understood differently by parents and healthcare workers within the Saudi context.

3.9.2.2 Lack of information provision

Consistent with previous literature in the Western context (Garant et al. 2002; Dickens et al. 2010; Pickering and Busse 2010; Morgan and Tan 2010; Schreiber et. Al 2011; Arnadottir and Egilson 2012; Saleh and Almasri 2013; Myrhaug et al. 2014; Wang et al. 2014; Sršen et al. 2014; Stefansdottir et al. 2015; Molinaro et al. 2017; Kang et al. 2017; Alnajjar & Elarousy 2017; Terwiel et al. 2017; Shevell et al. 2018; McManus et al. 2019; Antunes and Vaz 2021; Manzuma et al. 2021; Poojari et al. 2021), parents of Saudi children desired more information about their child's condition, treatment, and the specific treatments provided in pediatric intensive care units (PICUs) (Alnajjar and Elarousy 2017). In fact, they considered information provision as a key family need, in which information and updates regarding the child's medical care were highly valued as it gave them confidence in their care (Alnajjar and Elarousy 2017). This suggests that lack of information is a major issue shared by different contexts and cultures, which needs to be further investigated and addressed within the context of family-centred care provision.

3.9.2.3 What parents value in family-centred care

In Saudi Arabia, Alnajjar and Elarousy (2017) revealed how the parents considered their ability to express their concerns to doctors on daily basis, and to have their questions answered honestly to be items of high importance to them in clinical settings. In agreement with the parents, the nurses and doctors working at the PICU perceived their ability to answer the parent's and family's questions honestly, and providing the optimum care they can provide to families as the most important family need in PICU. In accordance with previous research like the studies of Morgan and Tan (2010), Wang et al. (2014), Terwiel et al. (2017), and Argall et al. (2021), the findings support the belief that parents need to feel listened to and respected by their healthcare providers.

3.9.2.4 Barriers to family-centred care

According to Alabdulaziz (2017), cultural and religious norms in Saudi Arabia were identified as barriers to the provision of services and, more specifically, family-centred care. The presence and involvement of male carers inside the rehabilitation setting are not acceptable by the community, which limits the participation of all family members. Another barrier to FCC was the language difference between healthcare workers and parents, as most nurses do not speak Arabic, the native language of all Saudis, which limits communication and interaction between both parties. There may be different barriers to FCC present within the Saudi Arabian context, which need to be explored further. Furthermore, although the themes revealed were limited, they represent the lack of research conducted within the Saudi context, as research concerning FCC was very confined to two studies from different healthcare fields, paving the way for further research to be conducted.

3.9.3 The Effect of Family-Centred Care on Child, Family, and Health Service Outcomes

In a Cochrane review, Shields et al. (2012) evaluated the effects of family-centred care models on child, family, and health service outcomes, comparing them to standard care models for hospitalised children aged 0 to 12 (premature neonates excluded). This updated review included one randomised controlled trial (Bolton 2004 cited in Shields et al 2012) with 288 participants, examining the postoperative nursing care provided to children who had undergone tonoplasties. The impact of family-centred care (FCC) on children, families, medical staff, and healthcare outcomes was evaluated by comparing children receiving standard nursing inpatient care to those receiving care in a care-by-parent unit (CBPU), implementing a holistic FCC approach to care. In CBPUs, children faced a significantly lower risk of receiving inadequate care compared to those admitted to a standard inpatient facility, yet neither their behavioural nor physical outcomes were significantly different. Nonetheless, parents expressed greater satisfaction with CBPU care than with standard care, both pre and post-discharge. Additionally, the costs associated with CPBU were also lower than those of standard inpatient care.

This review indicates that family-centred care may positively affect outcomes such as adequacy of clinical care, parental satisfaction and costs. While the scope of the review was specific to nursing, its findings can be applied to other healthcare disciplines that aim to address and integrate the holistic FCC approach to care. Indeed, family-centred care can be advantageous for any multi-disciplinary team caring for a child, particularly those focusing on the child's physical, mental, and emotional health, such as in physiotherapy.

3.10 Gap in the Literature and Conclusion

The literature on family-centred care for the rehabilitation of children with disabilities identified 10 themes, all of which are considered aspects of FCC. These themes were revealed both in the Saudi context and the global context, with some themes being prominent within many studies, whereas others were less prominent. Nonetheless, in accordance with the literature, all of the themes previously disclosed are thought to be connected as they all relate to the concept of family-centred care as perceived by families and healthcare providers.

Studies worldwide have explored family-centred care in rehabilitation settings and explored the perceptions of families and healthcare workers using various methodologies in an attempt to evaluate rehabilitation services, leading to outcomes shaped by the diverse perspectives of the sample and the methodology used. In addition, it is clear from the literature that most studies relied on the MPOC questionnaire, which appears to dominate the literature. In spite of the reliability of the MPOC measure, it merely evaluates the processes in which care is provided and not the meaning of parents' and physiotherapists' lived experiences of family-centred care nor the philosophies and perspectives associated with this approach, as Shields (2015) implied. This suggests the need for further research, and therefore, the purpose of the present study is to explore how participants understood, perceived, and interpreted their experiences of family-centred care in Saudi Arabia, as well as the meaning attributed to these experiences.

In general, there was a lack of literature relating to parents' and physiotherapists' lived experiences of family-centred care, especially in Saudi Arabia. As a consequence, and based on the recommendations of previous literature, qualitative research is highly recommended as a means of better understanding FCC and expanding on its different elements within the context of Saudi Arabia. To the researcher's knowledge, no qualitative study has been conducted in a Saudi Arabian pediatric rehabilitation setting on the experiences of Saudi parents and physiotherapists with FCC. This has paved the way for this research, which will assist in improving the clinical practice of physiotherapists in Saudi Arabia in order to provide the most effective pediatric rehabilitation services for children with physical disabilities.

CHAPTER 4- RESEARCH METHODOLOGY AND METHOD

4.1 Introduction

This chapter describes the methodology and research method used to explore the lived experiences of mothers and physiotherapists in relation to FCC for the rehabilitation of children with disabilities. The chapter critically examines the philosophical and theoretical approaches that underpin the research process, particularly interpretive phenomenological analysis (IPA). Additionally, the chapter describes the study method and procedure, which includes obtaining ethical approval, the sampling method and participant recruitment, the interview process, data analysis, and measures taken to ensure the reliability of the research.

4.2 Research Question, Aim, and Objectives

The literature review (Chapter 3) revealed a lack of studies exploring the lived experiences of physiotherapists and mothers regarding family-centred care for the rehabilitation of children with disabilities in Saudi Arabia, which forms the basis for this study. As a physiotherapist who has worked with children with disabilities, I, as the researcher, was motivated to investigate these experiences in order to gain a deeper understanding of FCC.

4.2.1 Research Question

The following research question was formulated to guide this study, as follows:

What are the physiotherapists' and mothers' lived experiences and meanings of family-centred care for the rehabilitation of children with physical disabilities in Saudi Arabia?

4.2.2 Research Aim

The aim of this research was to explore the physiotherapists' and mothers' lived experiences and meaning-making of family-centred care for the rehabilitation of children with physical disabilities in Saudi Arabia.

4.2.3 Research Objectives

The research aim was further divided into the following objectives:

- To explore the personal lived experiences and meanings of physiotherapists and mothers of children with disabilities concerning family-centred care
- To explore the mothers' perceptions and meanings of the care received from physiotherapists in the context of family-centred care
- To explore the physiotherapists' perceptions and meanings of the care they provide in the context of family-centred care

4.3 Research Paradigm

According to Guba and Lincoln's (1994, p. 105) definition, research paradigms are sets of beliefs that determine how people perceive the world (Kivunja et al. 2017). A researcher's chosen

paradigm guides their philosophical stance, both epistemological and ontological, which in turn influences their research methods (Kivunja et al. 2017). Paradigms embody underlying principles of epistemology and ontology, providing a foundation for the researcher's thinking and understanding of the world (Kivunja et al. 2017; Liamputtong 2019). Understanding these underlying principles is crucial in determining the appropriate methodology for the research, including data collection and analysis methods. The paradigm chosen for this study helped define the research problem, develop research questions, determine the sampling procedure, select tools for analysis, and interpret the data (Liamputtong 2019). Therefore, this chapter outlines the chosen research paradigm and how it informed the research methodology.

4.3.1 Ontology and Epistemology

According to Snape and Spencer (2003), ontology refers to the nature of reality, the world, and what we can know about it. Social ontology, as defined by Bryman (2021), is a philosophical approach to understanding the nature of social entities, namely whether they are objective entities that exist independently of external actors or whether they are socially constructed through perceptions, actions, and interpretations within a society. Similarly, Ormston et al. (2014) state that ontology examines whether there is one universal reality or multiple context-specific realities and whether this reality is independent of human perception and interpretation. In essence, ontology is the study of how humans view reality and social life.

Epistemology, on the other hand, focuses on how knowledge is acquired and what is considered to be valid knowledge. According to Richards (2003), epistemology is concerned with how people think about knowledge, or how we find out about the world and reality. Crotty (2020) views epistemology as a way of understanding the world and includes knowledge and a specific understanding of what that knowledge means. Similarly, Cohen, Manion, and Morrison (2018) state that epistemology is concerned with the assumptions one makes about the nature and form of knowledge, as well as how it can be obtained and communicated. The kind of epistemological assumptions humans make about knowledge fundamentally impact how we approach

discovering and learning about social behaviour (Cohen et al. 2018). According to Ejnavarzala's (2019) recent review, a crucial aspect of epistemology is understanding what constitutes knowledge, how it is justified, and the theories of knowledge.

4.3.2 Types of Ontology and Epistemology

The different types of epistemological and ontological positions will be discussed to demonstrate the views adopted in this research.

❖ *Positivism and Objectivism*

Positivism, an epistemological position, emphasises the importance of objective evidence and objectivity when seeking truth, assuming that the researcher does not influence the world (Al-Saadi 2014). In positivist thinking, facts and values are treated as distinct entities, and the positivist viewpoint holds that objects in the world have meaning before one becomes aware of them (Al-Ababneh 2020), implying that the researcher should avoid influencing their research findings.

Moreover, positivist epistemology assumes that meaning and meaningful realities are already contained within objects, waiting for discovery and existing independently of any conscious experience (Crotty 2020; Al-Ababneh 2020). In this sense, recognising objects around us depends on discovering meanings that already exist and have been present in them all along. Additionally, the positivism/objectivism paradigm asserts that truth is eternal and inevitably objective. When the right approach is followed, it is possible to discover the objective truth in the individuals studied, where the true understanding of phenomena must be supported by evidence and measured (Hammersley 2013). According to positivist writers like Isaac Newton and Francis Bacon, the best ways to discover knowledge about the world involve "careful direct observation" rather than drawing conclusions from abstract theories (Ormston et al. 2014).

Despite this, positivist and objectivist thinking, and traditions have been criticised since the early twentieth century (Al-Saadi 2014). This rejection of positivism was based on the claim that if the rules and laws are derived only from observation, it is also possible that future observations may add to or contradict existing rules or laws (Ormston et al. 2014). This led to the development of the second version of positivism called post-positivism, which asserts that knowledge about the world is gained not only through careful observation but also through testing theories. This approach suggests that hypotheses should be derived from theories first before being empirically tested (Al-Saadi 2014).

❖ *Interpretivism and Constructionism*

The rejection of positivism and objectivism has led to the development of interpretivism and constructionism, opposing worldviews in which a constructivist adopts a relativist viewpoint that acknowledges that a given phenomenon can be interpreted in multiple ways rather than attempting to determine truth through measurements (Al-Saadi 2014; Pham 2018). These views contend that we can derive knowledge about the world from sources other than direct observation, namely, our views and interpretations of the world around us, where we strive to comprehend the perspectives of participants and investigate their sense-making using qualitative methods (Broom and Willis 2007; Al-Saadi 2014; Berryman 2019).

According to Ormston et al. (2014), our perceptions are the means by which we interpret the sensory information we receive, and, in this context, our understanding of the world derives from our reflections on events and experiences rather than only our lived experiences. Interpretivism and constructionism strongly oppose positivism and objectivism by arguing that knowledge arises from exploring and understanding (rather than discovering) the social worlds of the people being studied, focusing on their meanings and interpretations (Berryman 2019). This implies that researchers develop their own meanings and interpretations based on the interpretations of the participants (Pham 2018). In this way, the researchers become personally involved in the research and cannot be detached, and as a consequence, the findings are influenced by their

perspectives and values (Pham 2018). This opposes the positivism and objectivism approaches, where researcher must try to distance themselves from findings to avoid affecting study results.

4.3.4 The Link between Philosophy and Research: My Epistemological and Ontological Assumptions

The epistemological and ontological assumptions that I present here have informed my understanding of social research that is presented in this thesis and played a vital role in developing the research methodology. As a Muslim, my beliefs are shaped by the teachings of the Holy Qur'an and the sayings and traditions of the Prophet Mohammed (peace and prayers be upon him). In line with the ontological and epistemological approaches that underpin my research, I view the knowledge and reality revealed in the Holy Qur'an as the ultimate or absolute truth. Whilst I acknowledge the existence of other forms of knowledge and realities, I believe that they cannot be considered purely true.

Considering their divine origin, the knowledge and reality revealed through the Holy Qur'an about existence, nations, and events of the past, present, and future are unquestionable and considered to be pure truth. Nonetheless, not all knowledge has been revealed to humankind, and therefore, we must explore them as Allah says: "وَمَا أُوتِيتُمْ مِّنَ الْعِلْمِ إِلَّا قَلِيلٌ" translated into "and you were given only a little knowledge" (chapter 17, verse 85, p. 290). Allah the Almighty encourages us to contemplate our existence and understand the universe and the world around us. As a constructionist thinker, I believe that other forms of knowledge and realities exist, and it is our duty to investigate them, as outlined in the Holy Qur'an "إِنَّ فِي خَلْقِ السَّمَاوَاتِ وَالْأَرْضِ وَاخْتِلَافِ اللَّيْلِ وَالنَّهَارِ آيَاتٍ لِّأُولِي الْأَبْصَارِ" which is translated into "Behold! In the creation of the heavens and the earth, and the alternation of night and day, - there are indeed Signs for men of understanding" (chapter 4, verse 190, p. 75), which are understood in the context of human beliefs and perceptions. However, due to our inherent human biases and perceptions, our attempts to interpret and understand the world and its phenomena are limited, highly subjective, and approximate in nature.

In the view of Cohen, Manion, and Morrison (2018), we can only understand the social world from the perspective of the individuals who are part of the ongoing action under investigation. As an opposing view to objectivism, this means that there is no shared reality or meaning among people; instead, there only exists a number of individual interpretations, where interpretive approaches examine the social world from the perspective of culturally derived and historically situated interpretations (Al-Ababneh 2020). Furthermore, since people see reality through their beliefs and perceptions, there are many ways to interpret and view it, and knowledge is accordingly subjective because it is affected by both personal and contextual factors (Al-Saadi 2014). Therefore, views about reality can only be formed through human experiences and interaction and are socially constructed. In this sense, I find social phenomena to be the result of constant interaction between social actors. Additionally, people may construct meanings differently, even when they relate to the same phenomenon since each individual has their own perspective (Leavy 2022; Miller et al. 2018).

With respect to my epistemological position regarding the nature of reality and how it is constructed, I adopt an interpretivist view that contends that the researcher and the social world are intimately related, in which they are not inseparable but impact each other. Thus, the researcher cannot disengage from the research process in the course of the research; rather, they continually construct meanings and interpretations based on reflection and experience as well as those of their participants (Al-Saadi 2014; Berryman 2019). In this sense, understanding of the world and social phenomena, such as family-centred care in this study, was understood based on my interpretations and reflections of events as opposed to senses and careful observation as advocated by positivism (Al-Ababneh 2020). Additionally, the fact that the findings of the research are inevitably influenced by the researcher's viewpoint and values means that objective and value-free inquiry is inapplicable.

Furthermore, by exploring, understanding, and making sense of people's behaviour, perceptions, and interpretations of the world, instead of only observing and explaining these perceptions, a greater understanding of social phenomena can be gained. In this regard, quantitative research methods are inapplicable for the study of social phenomena such as family-centred care - hence

my use of qualitative research methods to explore my participants' perceptions and beliefs about family-centred care.

The research methodology and overall research design reflect the ontological and epistemological positions outlined above. The aim of this study was to explore, rather than discover, a part of the reality of family-centred care through the experiences, perceptions, and meanings of my participants within their unique context, whilst acknowledging the diverse views, perceptions, and experiences of these participants. Philosophical debates have arisen from the recognition that knowledge and truth can take various forms and natures, and thus different methodologies and approaches are used to study and comprehend these concepts. In this regard, the ontological and epistemological assumptions held by the researcher are critical in justifying the choice of research method and approach. Therefore, the selection of data collection, analysis, and interpretation should be based on the researcher's beliefs and what is being implied.

4.4 Qualitative Research

Qualitative research can be utilised by a variety of disciplines for a variety of purposes (Gill and Baillie 2018). It is a type of social research that focuses on how people make sense of their experiences and the world they live in (Holloway and Galvin 2016). It provides a scientific process to understand, describe and interpret a social phenomenon as lived by individuals and explores the behaviours and feelings underlining these experiences (Alharahsheh and Pius 2020; Holloway and Galvin 2016). In qualitative inquiry, the researcher tries to obtain an 'inside view' of the participant's experience in the search for the essence and structure of that experience (Holloway and Galvin 2016; Starks and Trinidad 2007; Berryman 2019). Additionally, researchers are interested in exploring a person's understanding of the world and their experiences within it (Merriam and Tisdell 2016).

Qualitative research used in healthcare looks at the words, language and context of an experience, rather than looking at numerical data, to capture and understand the holistic

perspectives and experiences of individuals (Creswell and Poth 2016; Green and Thorogood 2018). It seeks to shed light on meanings that are less perceptible. In fact, in such research, an attempt is made to explore the complexity of the social world, where the inductive nature and common approach to questions such as 'what, how and why' differs from quantitative studies, which emphasise 'how much, how many and when' (Tuffour 2017). Although it has been extensively used in the social sciences, such as anthropology and sociology, there has been a broader use of qualitative research in the educational, nursing, psychological and medical fields as well (Liamputtong 2019). Indeed, qualitative research can include healthcare studies that address the understanding of human health, health behaviour and services (Green and Thorogood 2018). It can further be used to uncover knowledge about topics or phenomena that are not well understood, or which are less well known (Tuffour 2017).

This research excluded Ethnography, Case study, and Action research, as they did not align with the research question, aim, and objectives. The detailed exclusion procedure can be found in the appendixes (Appendix P). After excluding the above theories, Grounded Theory, Narrative Inquiry, Descriptive Phenomenology, and Interpretative Phenomenological Analysis (IPA) were explored in-depth to ascertain which one was most suitable for the research question and objectives.

The strength of Grounded Theory stems from its cyclical process of data collection and analysis, provisional coding, and further data collection and analysis until saturation is achieved. This process moves from inductive to deductive phases, moving backwards and forwards, in which emergent themes and theories are tested (Green and Thorogood 2018). Although Grounded Theory is typically employed when little is known about a topic (Holloway and Galvin 2016), Family-Centered Care (FCC) is a well-known concept and theory that has been explored in both adult and paediatric care worldwide. Additionally, Grounded Theory is not primarily descriptive and does not investigate the perceptions or experiences of individuals (Holloway and Galvin 2016). Instead, it aims to generate concepts and theories to explain a fundamental social process or explore key concerns and their resolutions, which is not the objective of this PhD research (Starks and Trinidad 2007; Holloway and Galvin 2016).

Narrative Inquiry, a qualitative approach, focuses on the experiences of an individual, such as suffering, illness, well-being, or quality of life, and how their personal perspectives affect these experiences (Holloway and Galvin 2016). However, it was not selected for this research due to three main reasons. Firstly, it generally emphasises on individual experiences, typically representing a single case or a small number of cases (Savin-Baden and Major 2022; Creswell and Poth 2016). In contrast, this study aims to examine both the ideographical and shared meanings of a phenomenon as experienced by a group of individuals in order to obtain a holistic overview of family-centred care for the rehabilitation of children with disabilities. Secondly, narrative inquiry is centred on storytelling, with a beginning, middle, and end (Savin-Baden and Major 2022; Holloway and Galvin 2016). However, the current study explores the meaning of the lived experiences of mothers and physiotherapists regarding the FCC provided to children with disabilities and investigates the interpretations of these experiences and realities. Lastly, bias and truth are significant issues in narrative research, as researchers cannot validate the truthfulness of the story being told due to potential discrepancies between the original story and the retold version (Savin-Baden and Major 2022; Holloway and Galvin 2016). Although participants in this PhD project were asked to recall recent events that happened (within six months to a year), the nature of narrative inquiry (if it were applied) might have triggered events from the distant past to help participants initiate their stories. This is where recall bias might occur and impact the research findings. After excluding the theories discussed above, IPA was determined to be the most appropriate theory for this PhD project and will be explored in further detail in the following section.

4.4.1 Interpretative Phenomenological Analysis (IPA)

Overview

IPA is a research method that originated in psychology and has since gained popularity across health and social sciences as a way to interpret and understand complex, emotionally charged topics, such as illness experiences (Finlay 2011; Smith et al. 2019). IPA focuses on how individuals perceive their experience in the lifeworld or, in other words, what that experience means to them, providing a detailed exploration of the participants' views on the studied topic (Teherani et al. 2015). IPA is an inductive approach in which themes are drawn from the text, and it involves a two-stage interpretation process called a double hermeneutic (Smith 2015). The two stages of interpretation are about the participants making sense of their world and the researcher trying to make sense of the participant's understanding of their world (Smith 2015). It is an approach used by researchers who aim to find out how individuals perceive a certain experience and how they are making sense of and understand that experience to learn from it and to obtain new insights into a certain phenomenon (Smith 2015; Neubauer et al. 2019). IPA was used within this thesis because of its permissance of in-depth analysis on the individual level followed by group-level analysis.

4.4.1.1 IPA Underpinning Theories

There are three theories underpinning IPA, which are phenomenology, hermeneutics and idiography (Larkin and Thompson 2012; Love et al. 2020), which will all be discussed in the following section.

❖ *Phenomenology*

Phenomenology is the study of human experience and how that experience is perceived and appears to the conscious (Holloway and Galvin 2016; Savin-Baden and Major 2022). The founder of phenomenology, mathematician Edmund Husserl, attempted to differentiate between one science and another by establishing the fundamental concepts of these disciplines based on how they appear to us in our experience of them (Dan Zahavi 2018). Later, many psychologists used his approach to understand certain aspects of the human experience of the world (Neubauer et al. 2019). Although there are many types of phenomenology, they all share two main principles: focusing on the human experience and emphasising the concept of intentionality (Eatough and Smith 2017).

According to Husserl, intentionality is the primary feature of consciousness, and it is not concerned with doing something intentionally, which is the usual meaning of the word; instead, it is about the fact that whenever someone is conscious, they will always be conscious of something (Damsgaard 2020; Smith and Nizza 2021; Fuchs et al. 2019; Leavy 2022). Indeed, in phenomenological psychology, the main focus is not on understanding cognition and looking inside people's heads to explore what is happening, but instead, it focuses on experiences as they appear to and are perceived by one's conscious (Holloway and Galvin 2016). This leads to two new terms used in phenomenology, which are *noema* (what is experienced) and *noesis* (how it was experienced) (Leffert 2015). Intentionality is the correlation between *noema* and *noesis*, and this correlation helps distinguish between the two main types of phenomenology: transcendental and existential phenomenology (Langdridge 2007; Leffert 2015). Transcendental

phenomenology, also known as descriptive phenomenology, aims to explore the essence or structure of experiences as they are perceived by our consciousness. In this approach, descriptions of experiences are based on data and do not take into account external theories (Tuffour 2017). This method aligns with Husserl's philosophy, which emphasises the ability to transcend experience and view the world from a higher perspective (Tuffour 2017).

In contrast, existential phenomenology, also referred to as interpretative phenomenology, focuses on interpreting data and understanding their meaning, rather than just describing them. This approach is consistent with the aim of this research (Larkin and Thompson 2012; Smith and Nizza 2021). Existential phenomenology is concerned with our existence and our experience of the world as we live it (Holloway and Galvin 2016; Savin-Baden and Major 2022). Interpretative phenomenology, influenced by the philosophy of Heidegger and Gadamer, emphasises the comprehension of the meaning of an experience, rather than just seeking its essence (Larkin and Thompson 2012; Savin-Baden and Major 2022). Additionally, it highlights the emotional responses of participants and the role of language in conveying findings (Engelland 2021).

Hermeneutics, or interpretative approaches, reject the idea of reduction and acknowledge that personal opinions cannot be suspended in favour of interpreting experiences (Tuffour 2017). In fact, in IPA, researchers recognise that biases, preoccupations, and assumptions will inevitably influence their research inquiries and strive to engage with them meaningfully to achieve understanding, as Gadamer suggested (Eatough and Smith 2017). Heidegger's interpretative phenomenology heavily influences IPA, as it captures the lived experience and takes the context as part of identity and a way of providing meaning to an experience (Larkin and Thompson 2012).

❖ *Hermeneutics*

Hermeneutics is the second major theory underpinning IPA, with interpretation as its defining characteristic (Tuffour 2017). Although its origins lie in the interpretation of biblical and other historical texts, hermeneutics is now integrated into various schools of qualitative research and has become an essential part of many fields of study (Alharahsheh and Pius 2020; Smith and Nizza

2021). According to Kinsella (2006), hermeneutic thinking informs qualitative research, which aims to understand and interpret meaning rather than explain and verify (Adler 2022). Hermeneutics acknowledges the role of language and historical context in interpretation, in addition to the position of interpretation itself (Schmidt 2016). Language is used not only to describe information but also to express experience, particularly when expressed poetically, figuratively, and rhythmically (Tuffour 2017). Hermeneutic theorists use interactive and textual interpretations to reconstruct the meaning of texts through their subjective expressions (Tuffour 2017).

Furthermore, hermeneutics regards the relationship between the part and the whole as a significant aspect of IPA (Eatough and Smith 2017; Tuffour 2017). The hermeneutic cycle suggests that to understand any given part, one must see the whole, and to understand the whole, one must see the parts (Smith et al. 2009, p.28). During the analysis process, various ways of deconstructing and rebuilding the experience should be considered. A crucial element of IPA is to encourage participants to describe and reflect on their experiences. Participants interpret their experiences and make sense of them, whilst researchers engage in an interpretative process, attempting to make sense of what participants tell them, which is referred to as double hermeneutic (Shaw 2010; Smith and Nizza 2021). As a researcher, using this method helped me acquire knowledge about my participants' world by focusing on their experiences, interpretations, and the meanings attributed to these lived experiences.

❖ *Idiography*

The third theory underpinning IPA is Idiography, which focuses on the particular lived experience of an individual (Larkin and Thompson 2012; Love et al. 2020). In idiography, the goal is to understand the concrete, specific, and unique aspects whilst preserving the integrity of the individual (Eatough and Smith 2017). The idiographic nature of IPA is characterised by researchers' commitment to examining the phenomenon as experienced by specific individuals within a particular context (Smith and Nizza 2021). Hence, IPA provides analytical processes that

enable the development of more general statements from single cases whilst maintaining traceability to the particular claims of the individual participants (Eatough and Smith 2017; Smith et al. 2012; Larkin and Thompson 2012). The idiographic nature of the data allowed me to recognise the unique meanings and experiences of my participants, identify common experiences, and draw conclusions about possible shared phenomena. Phenomenology is characterised by the inclusion of personal, contextual experience as well as universal and relational phenomena (Smith and Nizza 2021).

❖ *The rationale for choosing IPA*

The aim of this research was not merely to collect quantitative data or descriptive information but to comprehend experiences and seek meanings and interpretations. Therefore, IPA was selected for this thesis as it is an interpretative methodology that focuses on understanding the interpretation of experiences related to particular phenomena, offering profound insights both at individual and collective levels.

Firstly, IPA differs from traditional phenomenological approaches in its preference for individual accounts (idiographic) over shared similarities concerning the phenomena of interest. While participants may share a common experience, their interpretations might differ due to personal or contextual factors. An IPA study attempts to understand the entirety by gaining more knowledge about a single case. The information derived from a single case is not generalisable but seeks to shed light on the whole, broader context. Given that the care of these children is so personal and unique, the focus of the ideographic was critical for this study.

The second significant aspect is the double hermeneutical approach, where the results of the study are a reflection of our attempts to comprehend and make sense of what the participants themselves are experiencing. My interpretative lens, influenced by my beliefs and my background as a Saudi Arabian woman and a physiotherapist, inevitably influences this

understanding and interpretations. My identity, beliefs and cultural values are intertwined with my perspective, making it impossible for me to separate myself from this cultural backdrop.

Unlike other phenomenological approaches that require the researcher's detachment, true descriptive phenomenology aims to side-line the researcher focusing solely on the participant's narrative, IPA embraces the researcher's world as part of the research process. IPA asserts that researchers cannot completely detach and acknowledges the fact that the outcomes are the result of the researcher's interpretation of the participant's sense-making. This perspective encourages the researcher not to be an objective observer, but to embrace their role as part of the research process and use it to shape the research.

In light of the above, IPA was chosen for this study.

4.5 Research Methods

4.5.1 Sample Size

Creswell (2012) highlights the importance of sample size, stating that it is essential to determine the size of the sample a researcher will require before selecting participants for a study. According to Smith (2015) and Langdrige (2007), IPA data are collected using purposive sampling of a relatively small homogenous sample size of 5-6 participants due to the required level of detail from the individuals' experiences and the amount of data generated by IPA. This implies that the researcher would look for a predefined group of individuals for whom the research question is significant (Smith 2015). For the current research, the sample was recruited from hospitals and centres that provide physiotherapy treatment for children with physical disabilities in Saudi Arabia. The sample size decided upon was primarily 6-8 participants as Smith (2015) believes that a sample of this size offers the best opportunity to examine the similarities and differences between participants' experiences. Nonetheless, he warns researchers about being overwhelmed by the increased number of participants and increased amount of data generated. Therefore, a total of four physiotherapists and four mothers were interviewed in this research (two from each centre).

4.5.2 Participant's Inclusion and exclusion criteria:

Mothers		Physiotherapists
	Mothers of: <ul style="list-style-type: none">○ Children with disabilities aged 2-14 years (which is based on the average age range of children treated)	Qualified Physiotherapists (registered by the Saudi Health Commission or Ministry of Health)

Inclusion Criteria	in paediatrics hospitals/rehabilitation centres in Saudi).	
	<ul style="list-style-type: none"> ○ Children with a confirmed diagnosis of physical disability. ○ Children with any form of physical disability 	
	Mothers who can read and understand the spoken and written Arabic language, to ensure their full understanding of research process.	Physiotherapists who can either: <ul style="list-style-type: none"> ○ understand written and spoken English ○ understand written and spoken Arabic ○ or understand both languages
	Mothers who are Saudis, as the study represents the Saudi mothers' experiences.	Saudi and non-Saudi nationals, as healthcare workers are multi-national
		Both Male and Female physiotherapists
Exclusion Criteria	Mothers of: <ul style="list-style-type: none"> ○ Children with disabilities aged <2 or >14 years. ○ Children with disabilities with accompanying critical medical condition (e.g. Children in palliative care) 	Non-qualified physiotherapists
	Mothers who are not Saudis, as the study represents the Saudi mothers' experiences.	Undergraduate physiotherapy students
	Illiterate mothers, who cannot read or write, as this might affect their understanding of research process.	Other therapists (occupational therapists, Speech-language pathology therapists, etc.)

Table 4 Participants inclusion and exclusion criteria

4.5.3 Participants Recruitment

Data were collected from four different hospitals and rehabilitation centres which provide physiotherapy services for children with disabilities. I aimed to include participants from both governmental and private centres and organisations in the study; however, the achievement of this aim was completely dependent on gaining access and approvals from the Saudi Ministry of Health (MOH) and private centres. The Saudi MOH granted me access to three governmental hospitals. Access was gained from one charitable semi-private rehabilitation centre in one of the Kingdom's largest cities. The head of the physiotherapy department in each setting served as the gatekeeper, permitting me to access the facility to leave my study invitation at the department's reception desk. The gatekeeper in other settings distributed the study invitation to both parents and physiotherapists. In both cases, those who were interested in participating contacted me and arranged an interview. A gatekeeper is an individual within an organisation who has the authority to grant or deny access to individuals or locations during a research study, and in social research, gatekeepers are essential mediators for gaining access to study settings and participants (Andoh-Arthur 2020). However, as the principal investigator, it was my responsibility to assess or confirm the eligibility of participants prior to consent.

4.5.4 The Use of Interviews

Interviewing is a common method utilised to gather data for qualitative research, and it can be described as a systematic approach to conversing with and listening to individuals (Croix et al. 2019). The interview was selected as the method of collecting data because it has proven to be a powerful method for reflecting on participants' experiences in qualitative research. In IPA, data are gathered using semi-structured interviews with open-ended questions to allow for the flexibility of exploring other areas or topics emerging during the interview (Leavy 2022). In fact, semi-structured interviews have the advantage of ensuring that the same topic is covered in each interview while at the same time allowing some flexibility for the interviewee to add their own

interpretations and associations (Croix et al. 2019). The interviews were tape-recorded and then transcribed verbatim so that during the interview I could actively listen and carefully focus on what was said. In order to gather more comprehensive information, one-to-one semi-structured interviews were conducted with both physiotherapists and mothers of children with disabilities rather than using focus groups (Guest et al. 2017).

Focus groups were considered as a data collection tool. However, given the conservative nature of Saudi culture, I felt as a researcher that the sharing nature of focus groups might make participants feel uncomfortable and anxious. It is imperative for the researcher to create a safe and comfortable environment for the participants; this presents a challenge if using a focus group as participants need to trust the researcher as well as trust all of the other participants (Croix et al. 2019). In fact, it might be problematic for physiotherapists and mothers to discuss sensitive matters regarding care delivery or care provision in front of others in a focus group due to the possible power issues that can arise when using such an interview method. Indeed, parents and professionals occupying different positions of power and authority have been shown to be major obstacles to creating a successful parent-professional partnership in the care of children with disabilities in a clinical setting (Cohen and Mosek 2019). Having this in mind, an assumption was made not only that the power imbalance could affect the relationship between therapists and parents in terms of service provision but that it could possibly impact upon the disclosure of information during the interview.

McGrath et al. (2018) emphasised the importance for the researcher to consider the explicit and implicit power relations in interviews between, for example, students and healthcare teachers as the former might try to provide what is perceived to be a response that pleases the latter. Furthermore, it is also possible that individuals will not be able to voice their differences or opinions in a group setting as a problem arises when the more vocal participants, or those in a senior position or power, dominate the discussion while the others do not speak (Croix et al. 2019). In light of the above, individual interviews were selected as the method of data collection. Additionally, for the purpose of preventing power relationships from impacting what was disclosed, I as a researcher constantly reassured my participants, both mothers and physiotherapists, that I was there for the purpose of conducting the research and to enable them

to have their voices and experiences heard. Thus I was encouraging them to speak up and ensuring them that whatever was said would remain between us and was confidential.

The interviews were conducted in person i.e. face to face, as they were thought to allow some form of flexibility in which the interviewers may allow respondents to engage, ask questions, and change the direction of the discussion, thus distributing the power equally (DeJonckheere and Vaughn 2019, Kakilla 2021). Indeed, semi-structured interviews provide an opportunity to establish rapport with the research participants and to encourage meaningful reflection and discussions (Rubel and Okech 2017).

In the literature, face-to-face interaction between researcher and participant has typically been considered the ideal method of gathering data from interviews, the gold standard (Novick 2008). In fact, the interaction between the researcher and participant in a face-to-face interview promotes a more natural environment that allows small talk, non-verbal communication (Kakilla 2021), joking and politeness between parties, which encourages open communication and comfort (Shuy 2002 in Gubrium and Holstein 2011). Additionally, physical presence helps ensure that obvious clues related to the respondent's confusion or unwillingness to answer a certain question are visible and accessible to the researcher, which in turn allows the interviewer to rephrase a question or frame the context in order to promote a response (DeJonckheere and Vaughn 2019). This has encouraged me as a researcher to conduct personal interviews with my participants, to engage with them, allowing them the flexibility of reflecting on their own experiences and expressing any issues of concern to them. Indeed, Eatough and Smith (2017) state that interviews are the most common method for collecting data in IPA because of its flexibility as the researcher is able to facilitate the participant in exploring their lived experiences in real time as they interact with the researcher. Additionally, conducting face-to-face interviews gave me the opportunity to closely observe my participants' unspoken expressions and gestures related to their experiences and to thus gain a better understanding and interpretation of their experiences of family-centred care.

Braun and Clarke (2014) highlighted the strengths and limitations associated with individual (face-to-face) interviews. Using face-to-face interviews can provide detailed and comprehensive

information regarding individual perspectives and experiences as well as some flexibility to ask unplanned questions. It also requires smaller samples: in many cases, it is sufficient to conduct only a few interviews to obtain adequate data. In contrast, some of the limitations of individual interviews are the time required for conducting, transcribing and organising them. An interview can also take participants an hour to complete, making it a time-consuming endeavour.

On reflection of this process, I recall that, as a novice researcher, conducting in-depth interviews was overwhelming as I attempted to manage these interviews in a manner that facilitated flexibility and allowed participants to share their voices and stories while staying on topic. In addition, the process of transcribing and analysing such in-depth interviews was time-consuming and took longer than expected. As part of that process, however, supervisory support was provided to ensure that the data were analysed correctly and sufficiently. In spite of these drawbacks, as well as the time-consuming nature of IPA interviews and analysis, my intention as a researcher was to conduct interviews because they offered flexibility in terms of data collection procedures as well as the ability to elaborate on the experiences that were discussed during the interview, enabling participants to express concerns and reflect freely about these experiences.

4.5.5 The Use of an Interview Guide

I followed a semi-structured interview guide with open-ended questions for both physiotherapists and mothers that was developed in accordance with previous literature. According to Alase (2017), it is imperative that the questions are phrased in a probing and open-ended manner for the purpose of capturing the essence of what the research study seeks to uncover. In IPA research, an interview guide is usually to steer the researcher rather than to dictate the interview process (Eatough and Smith 2017). Reinharz (1993 cited in Braun and Clarke 2014) believes that a good interview guide will help to build trust and rapport between the researcher and participants so that they feel comfortable when sharing their personal information. Additionally, well-structured questions and communication are essential for the capture of rich and in-depth data relevant to the research question (Braun and Clarke 2014). The

guide was altered based on the preliminary data analysis as well as the researcher's notes, which offered a greater understanding of the participants' experiences while maintaining flexibility during the interviews. In fact, McGrath et al. (2018) suggest that it is useful to refine the interview guide during the interview process by adjusting the questions after the initial interviews as some questions may be misunderstood while others might be irrelevant or outside the scope of the study.

Reflecting on the use of an interview guide, I found it helpful to have a schedule to follow as it provided a script, but it took some flexibility and confidence to go with the flow of each participant's story. Although I was aware that their experiences were central to the study, I felt I had a duty to make sure they were doing it correctly as I wanted to collect relevant data for the research question and be able to use these scripts as guidance, given that I am a new researcher. As I conducted subsequent interviews, the approach became more iterative in that I learned to probe more spontaneously and individually in response to the answers to the first question.

4.5.6 The Language Used during Interviews

Although Arabic is the primary language in Saudi Arabia, the interviews with physiotherapists were carried out in both English and Arabic languages, and they were offered the opportunity to choose the language they preferred. Three physiotherapists conducted their interviews in the Arabic language, and only one conducted the interview in English as she was a non-Saudi therapist who did not speak Arabic. Alternatively, with parents, individual interviews were conducted in Arabic since it is the mother language of Saudis. Interviews were recorded on an audio recorder (consent was obtained from the participants prior to the interview). The use of recorded interviews was crucial to understanding and identifying the presence or absence of congruence between the respondents' statements, the manner in which they were said, and their behaviour during the interview. As Smith et al. (2009) imply, in IPA, it is necessary to maintain a verbatim record of the data collection process. Thus, without digitally recording the interview

process and exploring the questions asked, it would have been very difficult to conduct the interview required for this thesis.

In addition to this, written notes were taken while interviewing the physiotherapists and mothers. These written notes included important points, possible links and reflections. It has been argued by Anstey (2012) that a note-taking approach adversely impacts upon the conversational, free-flowing and responsive approach used to collect rich information. However, it helped me as a researcher to better understand what the participant was saying, remember important details, such as what a participant might have said, and ultimately identify important statements and highlight new, insightful topics that may not be addressed in the interview guide. All Arabic interviews were translated into the English Language by the researcher, and then the interviews were transcribed and coded. Data were then analysed and carefully examined following Smith et al.'s (2009) guidelines; details are provided in the qualitative data analysis section (Section 4.6).

4.5.7 Data Translation and Management

In their study, Halcomb and Davidson (2006) suggest that verbatim transcription is a difficult and time-consuming process that is negatively affected by technical difficulties, such as misinterpretations of the data generated, cultural differences and linguistic errors. This issue has been controlled in the current research by taking notes during all interviews, enabling me to capture thoughts and interpretations after listening to the audio recordings.

Having participated in the interview process myself, I felt that I would have a better understanding of my participants and be able to effectively capture the important points reflected in the interviews by translating the interview data myself. It was a time-consuming and difficult process to translate everything from Arabic to English, especially in terms of finding words in English to reflect the complex meaning of the original Arabic text. All efforts were made to translate the Arabic idioms used by my participants into appropriate English language.

As a means of gaining familiarity and comprehension, I read and listened to the transcribed documents multiple times, re-read the transcribed texts and re-listened to the recorded interviews as necessary. Through the use of this method, it was anticipated that there would be a reduction in the impact of researcher bias and an increase in the accuracy of recording what the participants said.

4.5.8 Interview Setting

According to Alase (2017), the participants should be allowed to choose the date, time and place for their interviews, and the researcher's first preference and choice must always be to meet at the location most comfortable for the participant for their convenience.

Considering the above statement, as well as the comfort and choice of the participants, the interviews were conducted in the hospitals and centres where the physiotherapists were working, and the mothers attended sessions with their children with physical disabilities. Interviews were conducted in a quiet and private meeting room at each facility and not at the participant's homes as I wanted the participants to feel comfortable and relaxed. Culturally and socially, conducting interviews at home may not be feasible since some may be uncomfortable with the presence of a stranger in their home. Indeed, Holloway and Galvin (2016) are concerned with the safety of the researcher and believe that conducting interviews in the participant's homes could be problematic. As Alase (2017) states, the participant's comfort is the researcher's priority for safety and comfort purposes; however, the researcher should provide an alternate meeting place (such as a restaurant, coffee shop or any other appropriate location) when needed. Gill and Baillie (2018) imply that, for purposes of confidentiality, it is preferable to conduct the interview in a quiet location so that the researcher and participant may concentrate on the conversation as well as facilitate an accurate audio recording of the interview. This was ensured by following the lone-worker policy attached in Appendix (Q).

Interviews were conducted in the hospital in a quiet, private room, arranged by the head of the department, who was informed of the timing and end of the interview to ensure participant and

researcher safety. A potential limitation of conducting interviews in a hospital setting was the possibility of interruptions to the interview by the therapists, who may need the mother’s assistance with the child, or interruptions by other physiotherapists who require the therapist being interviewed.

The interviews with participants were carried out separately, with each mother and each physiotherapist being interviewed individually as physiotherapists might not feel comfortable being interviewed in front of parents and vice-versa. The interviews with mothers were carried out during their children’s regularly scheduled therapy sessions so they did not feel burdened by an extra trip to the hospital. On the other hand, interviews with the physiotherapists were completed at a convenient time for each therapist when they were not actively treating patients to ensure that my research did not interfere with their work obligations and responsibilities. The table below (table 6) shows information about the clinical setting from which data were collected, with all clinical setting names replaced by pseudonyms.

<i>Clinical Setting</i>	<i>Name</i>	<i>Type of Setting</i>	<i>Physiotherapist</i>	<i>Mother</i>
1	<i>Salamago Centre</i>	Charitable Rehabilitation Centre	Hanaa	Wed
2	<i>Mulberry Hospital</i>	Governmental Hospitals	Adam	Mona
3	<i>Whoville hospital</i>		Maya	Basmah
4	<i>Roover Hospital</i>		Rasha	Salma

Table 5 Clinical settings for data collection

4.5.9 Study Protocol

Participants were selected following a purposive sampling technique and according to a previously predetermined criterion (Table 1). The eligible applicants were given the study information sheet and contact information so that they could think about joining the research and were given 48 hours to reach a decision. I contacted potential participants who expressed interest in participating, and once this was done, the interview location and time were confirmed by me. On the day of the interview, I ensured that the interview room was properly set up for the interview and that refreshments were provided. In addition to preparing the interview set-up and the interview guide, I located the seating and the audio recorder properly. I greeted the participants so that they felt comfortable when they arrived and then introduced myself to the participants to make them feel relaxed. In fact, it is imperative for the researcher to establish a rapport with the research participants prior to any research interview in order for them to feel relaxed about the interview process before it begins (Alase 2017). An important factor for successful interviewing is the establishment of rapport, which allows the respondent to share details of their experiences openly (McGrath et al. 2018).

In addition, the interviewees were given the opportunity to look at the research information sheet and interview guide (see appendices J, K, L, M) and were informed of their rights. The participants were assured that they could withdraw from the study at any time and that their withdrawal would not negatively impact on their child's care or working relationships. The use of a research summary (information sheet) that is written in layman's terms can help inform the participants in advance about what will be discussed in the interview and why it is important to discuss it (McGrath et al. 2018). An informed consent form was obtained from the participants prior to the beginning of the interview and recording, and as soon as the interview started, I turned on the audio recorder and notified the participant. I conducted semi-structured interviews that lasted from 35 minutes to an hour and a half, using the interview guide, and after the interview ended, I thanked the participants for their time and turned off the audio recorder.

The participants were informed that they would be contacted, if needed, for further clarification of data. According to Alase (2017), there are a number of unpredictable variables that can arise during the interview sessions related to participants' actions or inactions in regard to their responses, which require further clarification and exploration. Therefore, when conducting phenomenological research, the researcher must devote a reasonable amount of time to conducting and concluding the participants' interviews in order to accommodate for any further follow-up interviews to be carried out should any verifiable information be discovered (Alase 2017).

4.6 Qualitative Data Analysis

As a researcher, I intended to reach beyond simply describing the lived experiences of mothers and physiotherapists with regards to FCC and look at that experience on a deeper level. In order to achieve this, I followed the guidelines of Smith (2009), starting the analysis of a single case, following a four-step analysis procedure before moving to the analysis of the next case. This process included moving from the specific to the general and from the descriptive to the interpretive and included various levels of analysis, including descriptive, conceptual and linguistic analysis.

These stages were as follows:

- *Stage 1: Reading and re-reading*, where the transcripts were read and then re-read and comments related to the meaning of particular sections were added on the left-hand margin of the transcript. These were descriptive, conceptual and linguistic comments that included interpretations, associations or summaries, and the main aim was to stay close to the meaning of the text and to state what was going on in the text.
- *Stage 2: Initial noting*, where the emerging themes were written in the right-hand margin to reflect a broader level of meaning. These were not fixed or finalised, and it was revisited many times.

- Stage 3: *Developing emergent themes*, where emergent themes were transferred to a separate sheet in chronological order. Then the sheet was cut into smaller pieces, and all the themes were spread out and organised on a large surface so I could view them properly (see figure 2). This helped me establish the common links between different themes, where some themes were clustered together and others were broken up further. This aided in re-ordering themes in a more analytical way and each theme group was named accordingly.
- Stage 4: *Searching for connections across emergent themes*, where a table of themes was produced in a cohort approach. Themes were named and linked to the originating text by referencing them to direct quotes.



Figure 3 Example of analysis- stage 3

Once these four procedures were completed, I moved to the analysis of the next case, repeating the stages and doing the analysis from scratch (Langdrige 2007; Smith et. al 2009). Flexibility was maintained when thematically analysing data, with some themes being excluded or added

throughout the different stages of data analysis (Smith et al. 2009). Upon completing this stage, I started to look for patterns across cases to gain a better understanding of these experiences and interpretations.

The IPA method of linguistic analysis is important for showing how the content, as well as the meanings of a particular experience, are articulated (Smith et al. 2009). Indeed, the language makes sense of how individuals make sense of their experiences, and from there how researchers make sense of participants' sense-making processes (Eatough and Smith 2006). Thus, the linguistic approach takes into account 'how' and 'what' the text can contribute to the meaning of the lived experience by taking a closer look at the participants' use of metaphors and binary opposites. In fact, Smith et al. (2009) highlight the importance of metaphors as a linguistic element that links descriptive notes to conceptual notes and has proven to be useful for describing lived experiences in the health and psychology disciplines. Indeed, the inclusion of quotes, metaphors and other contextual expressions is regarded as respecting and recognising the individual voices of participants in IPA studies (Miller et al. 2018).

As a novice researcher, considering the process of data analysis, it was evident that IPA would be easy to use due to its structured approach to analysis; nevertheless, it became apparent that the process was more complex, in part due to the need to engage both phenomenological theory and interpretation as well as to understand and integrate both. In order to overcome such difficulty, comprehensive reading took place throughout the analysis process and guidance and support were sought from supervisors when needed. I have found this to be beneficial in easing the pressure on me and ensuring that I am on the right course.

4.7 Ethical Framework for Healthcare Research

In healthcare research, the most important principle when conducting research is to do no harm. This principle comes under the four main biomedical ethics principles, autonomy, non-maleficence, beneficence and justice, that are pivotal to any research conducted in healthcare

(Holloway and Galvin 2016). Respect for autonomy means the participant's right to participate in the study freely and independently without being pressured to do so. The two principles of non-maleficence and beneficence indicate the need to do good and not do harm, in which benefits should always outweigh the risks for the individual participant and the wider society. The last principle is justice, which implies that the research strategies and procedures are fair (Holloway and Galvin 2016).

4.7.1 Ethical Considerations and Approvals

For the purpose of this study, I followed the Cardiff University Research Integrity and Governance Code of Practice (2019) throughout the research process. For this study, the proposal was submitted, and ethical approval was obtained from Cardiff University Research Ethics Committee (see Appendix A). Further approvals were sought from the hospitals and centres providing services for children with physical disabilities in Saudi Arabia, and this was done through the Saudi Ministry of Health (MOH) (see Appendix B) and the private centre directly (see Appendix C).

Information sheets included the research aim, proposed benefits, methods, potential risks (if applicable), the intention to use data and ethical values that I followed (see appendices J, K, L, M). Both the Arabic and English languages were used for all the forms to guarantee an accurate understanding of the study by the participants. Additionally, physiotherapists were informed that participation in the study was voluntary and that any decisions related to the study would not affect their employment. Furthermore, mothers were assured that their children's treatment was not affected by their participation in the interviews nor by the information they disclosed during the interview. In research, it is essential to inform the participants about the possible benefits, risks and implications of their participation. In fact, Karabwang et al. (2018) found that potential risks, direct benefits and possible adverse effects of an intervention were the three items that were most concerning to respondents in their study. In their multi-centre cross-sectional study, Karabwang et al. (2018) sought to find out what and how much information participants who are involved in biomedical research need and the kind of information they wish to participate in. Risks and benefits should, therefore, be explained thoroughly to research participants, as Karabwang et al. (2018) concluded.

Informed consent was gained from the physiotherapists and mothers who chose to participate in the interviews using a written consent form (see appendices H and I). This consent included permission to audiotape the interview, to use demographical data and to use the study results for educational purposes and research only (without jeopardising the participants' identity and confidentiality). Furthermore, the consent form included information on the physiotherapists' and mothers' right to withdraw from the study at any time without giving an explanation and stated that their decision would not affect their employment or child's care services by any means. The researcher acknowledges that when working with patients, some ethical issues related to imbalanced power between the researcher (physiotherapists) and the patient could arise (Holloway and Galvin 2016). In fact, some patients might feel they lack power over their right to participate or not and are not aware of their right to refuse participation. Thus, it was made explicit by me that it was within the participant's full right to make decisions related to participation or withdrawal from the study at any time. Additionally, participants were given 48 hours to think about participating in the study. According to Cowles (1988 cited in Holloway and Galvin 2016), timing is an important issue when contacting future participants as poor timing can prevent them from taking part in the study or making a rational decision.

The confidentiality and anonymity of the participants' identity was respected. Participants' names were substituted by their initials. With regards to the confidentiality of data, the study data were kept with me only. However, in case any information collected might cause concern for the participants' well-being or safety or the child's health and safety, I thought of explicitly sharing the information with the responsible person (the head physiotherapist or management). Furthermore, I followed the guidelines of the General Data Protection Regulation (GDPR) 2016, and thus the data collected in this research were anonymously stored and identification numbers replaced the participants' names to ensure confidentiality. Additionally, all the paper-based data and information were securely stored in a locked cabinet at my office, and all electronic information and data were saved on a password-protected hard disk and kept in the same locked cabinet at the office. All data will be retained for five years after the completion of the study. It will then be deleted in accordance with Cardiff University's Research Data and Retention Schedule 2023.

I followed the Cardiff University Research Integrity and Governance Code of Practice (2019) in terms of the guidelines related to reporting to supervisors. According to section 3.1 of the code of practice, the researcher is generally expected to report any issues related to the research to a group leader, lead investigator or supervisor in the case of student researchers. The supervisor of a research project is responsible for ensuring that all research students under their supervision are properly informed about the requirements of this code of practice and that they carry out their research in accordance with those requirements.

Prior to the start of the interview, the participants were given a chance to view the interview questions guide, and if they were not comfortable with answering the questions or participating, they had the right to withdraw. If during the interview, a physiotherapist or a mother did not feel comfortable answering a specific question, his/her decision was valued, and he/she was not forced to respond. Emotional or psychological support was provided to any participant who felt stressed or annoyed during the interview. In one instance, I stopped the interview and showed support to one mother as she seemed sad by comforting her until she felt better, and then the interview was resumed.

4.8 Researcher Involvement: Reflexivity

The concept of reflexivity refers to researchers reflecting on how their social positions relative to the research participants may interfere with their ability to maintain objectivity during the research (Adler 2022). I ensured self-evaluation throughout the entire research process in order to minimise biases from affecting objectivity. Having worked with children who have CP, musculoskeletal disorders and spinal cord Injuries and their families as a registered physiotherapist, I have developed expertise in treating these children. Being a Saudi female physiotherapist with the same cultural background as my research participants might lead one to assume that we are similar; however, my research participants were considerably different from me. As I conducted my research, I reflected not only on how cultural differences might lead

me to misunderstand them but also on how my social position as a female physiotherapist might influence how they spoke or acted in my presence. Accordingly, throughout the interview process, I encouraged them to speak up freely and openly, assuring them that whatever they said would remain between us and be kept confidential. The use of written reflexive notes throughout the interview process and research process was considered a valuable strategy that helped me as a researcher identify possible biases related to my position as a physiotherapist. It also helped me reflect on the different emotions and feelings I felt when recording interviews, reading transcripts and analysing data. According to Miller et al. (2018), it is important for researchers to reflect on their emotional reactions during the reading of the participants' stories by taking notes and discussing their feelings with other members of the research team when needed. Considering the vulnerability of these children and their families, I continuously encouraged myself as a researcher to stay focused on delivering the voices of my participants and ensuring that my interpretation reflected their actual lived experiences by analysing data very carefully and several times. This is because my end goal was to ensure that those people are delivered rehabilitation services that improve their health and well-being.

Throughout the entirety of the research, different approaches were utilised to guarantee the reliability of the study. One of these methods was an exhaustive and comprehensive analysis of interviews, in which the interview scripts were read and reread multiple times to guarantee that the essence of the individuals' real-life experiences was accurately captured and interpreted. The supervisory team was provided with an analysis of each interview that was conducted. In addition, the study's dependability was ensured by providing a comprehensive description of the methodology and design utilised in this study. This description included the participants' characteristics, the hospital's characteristics, the interview environment, the sample size and data collection procedures and analysis.

4.9 Conclusion

In this section, IPA and its underlying theories were examined. IPA is a relatively new qualitative research approach that has its roots in psychology but is widely used in health sciences and can be applied to different healthcare research, including physiotherapy. The combination of the three underpinning theories on IPA, which are phenomenology, hermeneutics and idiography, makes IPA distinct from other approaches within the phenomenological realm (Cassidy et al. 2011). Meaning is sought through listening to what is communicated and making sense of what is meant by the individual. Additionally, the IPA recognises participants as active, self-generating beings already immersed within a linguistic, cultural and physical environment (Smith and Osborn 2015). Finally, IPA's idiographic focus facilitates a deeper exploration of each physiotherapist and parent perspective and promotes a greater understanding of my participants' experiences of family-centred care.

Since the aim of my research was to obtain a deeper understanding of how family-centred care is experienced by both mothers and physiotherapists, IPA was a suitable fit with the current project as I sought to explore the meaning and interpretations of these experiences and not to seek descriptions. In addition, the idiographic nature of IPA and the ability to gain individualised accounts of experiences assisted me in interpreting and understanding the broader picture of family-centred care within the Saudi context. IPA is normally used for studies trying to reveal how participants perceive a specific situation and make sense of their personal and social world (Larkin and Thompson 2012; Smith 2015). Therefore, it is evident that IPA is useful for the facilitation of further exploration of the physiotherapists' and parents' lived experiences of family-centred care, aiding in answering the research question.

This chapter highlighted the rationale for using IPA as a research methodology, along with its underlining theories. It also shed the light on the data collection and analysis procedures, the strengths, and limitations of using individual interviews to collect data and the ethical considerations that took place throughout the study.

CHAPTER 5 – IDIOGRAPHIC EXPERIENCES OF PARTICIPANTS

5.1 Introduction

The purpose of this chapter is to present the findings of each participant based on their own experience and to emphasise the unique features of each experience. As for the shared experiences, they will be discussed in the following chapter (Chapter 6 - Cross-case analysis chapter). In this chapter, the idiographic experiences of the physiotherapists will be discussed followed by the ideographic experiences of the mothers.

5.2 Physiotherapists' Idiographic Experiences

5.2.1 Hanaa

❖ *Participant background*

Hanaa is a senior physiotherapist who had worked at the Salamago Centre for 11 years at the time of the interview. Hanaa is originally from India, where she took her undergraduate studies and worked in various hospitals. She had the opportunity to work with many different cases there, both adults and paediatrics. After that, she came to Saudi Arabia and worked as a general physiotherapist in one of the hospitals in a large city for about a year and a half. Then, she started to work at this centre. At the beginning of the interview, Hanaa showed a strong attachment to and pride for her Indian culture, describing how its values have been embedded in her since childhood. As I worked on analysing Hanaa's data, it became evident that some of her culturally based beliefs and values were reflected in her experience, perspective and treatment of children.

❖ *Interview room description*

The interview took place in one of the vacant treatment rooms that had not been used for that purpose for a long time; instead, it was used by the interns to place their belongings in the lockers. The room was small, with a treatment mat on the floor, a wardrobe and a single window. Hanaa sat on a treatment stool facing me, with her back to the window, and I sat on a rotatory chair facing her; my back was to the door, which was locked to ensure that no one would interrupt us. The recorder was placed on a bench between us, along with the papers for the study, such as the study information sheet and consent forms.

❖ *Hanaa's experience*

Hanaa's experience of family-centred care was unique in its nature. Her cultural background was evident in and throughout her narrative, as it influenced her practice and work ethic. She demonstrated a good understanding of what FCC entails, as she believed it meant involving the child's family in the rehabilitation process. Despite her belief in the significance of family-centred care, she did not perceive it as a component of her practice.

“What I guess is maybe I have maybe this vague idea that family is incorporated in the... ah... rehabilitation programme... ah... so it can be either because mostly over the past years and up till recently we are centre-based or school-based or community-based, and we just ignore the family, where this is the first place that needs attention.” (Lines 791 – 797)

Moreover, Hanaa reflected on her experience of educating mothers about their child's rehabilitation and how to perform exercises at home. As she described this, she felt that this guidance was extremely beneficial for mothers since it boosted their self-confidence.

“The first time the mother... ah... learn how to, this is like a preparation like how to after this session, how you’re going to deal with your child at home, so we are teaching all the home hands-on, actually hands-on, practice together with the supervision, so at least she is getting that confidence “okay this hand I’m doing correct”.” (Lines 318- 324)

Though Hanaa strongly believed that family was an important component of a child's life, she felt that cultural limitations hindered the involvement of family in a child’s care and altered the distribution of care roles within a family. According to Hanaa, Saudi mothers are perceived as the primary caregivers of their children and are therefore responsible for all aspects of childcare and household duties. On the other hand, fathers are perceived as the providers who take little responsibility for the care and, thus, lack knowledge about children with disabilities.

“Because the culture here... what I noticed since all my experience, the mother is the one main carer, the father is just a provider, so most of the things they do not know, even though parents mean father and mother.” (Lines 184-188)

Hanaa described this role as sometimes being highly demanding, especially when it coincided with other obligations, such as cooking, caring for other children and cleaning. In turn, this may negatively affect the mother's care and attention to the child with a disability, thus impacting on the child’s treatment and clinical condition.

“But you know the mothers say, “how can I deal with all, I have work at home, I have to take care of other children, I have to cook for the family, many things and have not only this job, I do not have anyone to help at home”. So these are the complaints 80%, no not 80%, 90% of the mothers we heard it, so that is why I am saying here more mother is the caregiver.” (Lines 194-200)

In Hanaa's view, the limited role of fathers was further hindered by the cultural boundaries that prevent men from entering a ladies-only facility, and the Centre was designed in this manner. Although this issue was not related to the management rules of the Centre, Hanaa felt that the father's entry into the Centre was something culturally unacceptable, describing it as "not very good". This could reflect the extent to which the father's presence was perceived as improper in Saudi society.

“Because here the culture somehow the father also not coming, and you know sitting with the communities where all ladies are there, it is not very good” (Lines 373- 375).

An evident conflict existed between Hanaa's strong desire to involve the fathers in the treatment room, promoting more FCC and the Saudi cultural barrier that prevented their entry and made changes to the rehabilitation setting difficult. She seemed saddened and guilty that she was not able to allow the fathers in even though she personally would not mind it as a healthcare professional, but she felt that culturally she was unable to do so.

“Because we are the ones talking about the family importance in the treatment plan, and we are the ones who are restricting the fathers to go inside, because of the culture. The thing is the therapists or the experts do not have any issues with the fathers entering into the system, but this is a community, the house community where other mothers are there, other children are there, so this is a barrier.” (Lines 384 – 390).

Hanaa suggested creating a separate section for fathers, which she believed would enable them to integrate into the treatment and become involved. She expressed a strong desire to make the fathers feel and experience the burden and complexity of caring for a child with disability, and to

share the responsibilities that mothers are bearing alone, so they could better understand how it feels and show their appreciation for the mother's efforts.

“So in the first place I think there should be a separate section where fathers can see the child also, and we can train them also so that at least they know the importance. Sometimes I am even hearing from some mothers that fathers say “Oh what is your job, you have nothing to do at home, take care of this child” like as if it is very simple to take care of a child with a disability. I mean she does not, they do not know that it takes that much time for each step, so at least he experiences in his hands and he understands how much it is difficult and how much it is important to take care of a child with a disability, you know.” (Lines 396 – 406)

Even with the influence of culture on role distribution, Hanaa believed the different roles that family members had in the child's rehabilitation were significant. In Hanaa's view, the entire family, including the mother, father, siblings and even nannies, plays an important role in the child's rehabilitation and development. She felt that the family's role was to help out with the child's care and share responsibilities with the mother by being aware of the child's condition and understanding how to deal with it.

“So the family has, I mean the wider role here, so of course here the problem is that the mother cannot only take care of everything, she also has another thing and herself she needs to take care of. So really all the family, each one, has a big role.” (Lines 261-268)

Though she strongly viewed the roles of all those in a child's life to be vital and essential, sometimes the incorrect or insufficient involvement of siblings was perceived as an interference that wasted Hanaa's efforts and impacted negatively on the child's progress.

“Also, I am seeing that those children are able to walk with a kay walker, they are pushing the wheelchair, so three hours we are training them for walking or whatever, and then after finish this, three hours of walking, they put him nicely in the chair and push him. So what is the use? What are we doing here? And what?” (Lines 516 – 521)

The nannies played a significant role in the care of children and assisted the mothers by sharing the responsibility for child care with them. Hanna drew attention to the mother's reliance on nannies for the child's care and how the nannies' high transition rate was considered a cultural barrier that hindered the child's development and progress, notably when nannies changed.

“And these nannies spend one year with this child, after that another nanny will come, with each nanny, then another nanny, so that is also another big issue that affects the child's... ah... improvement.” (Lines 426 – 429)

Hanaa pointed out that the roles of caring for a child with a disability may sometimes change and be affected by the separation of the parents, whereas in Saudi, the child is usually in the custody of the father, and only in rare cases is it the mother. In such a situation, the child is usually cared for by either the paternal grandparents or, more specifically, the grandmother. As the father has no caregiving experience, the child does not have the continuity of a single responsible caregiver. In her tone, Hanaa expressed disapproval and condemnation, suggesting that she was dissatisfied with the situation.

“Sometimes the grandparents are also taking part where the family is separated, the father and mother are divorced, and the child goes to the father’s side. Of course he does not know exactly what to do because all these years this child being held with the mother, and suddenly one day they get separated from each other, so really the father does not know anything about the child. So suddenly who is involved? Maybe the grandfather...I mean the grandmother. So in a lot of cases we are having like that also; the grandmother is the one taking care of the child.” (Lines 216- 225)

She felt the responsibility to explain to all family members how involvement in the child’s care was critical because it could significantly impact upon the child’s condition, either positively or negatively. Still, it was a challenging and lengthy process.

“So, it really is a big role in the family. Not only this but also lots of examples for us, how the child who really walks like the quadriplegic becomes diplegic if the mother is really really good. But even diplegic can go into quadriplegia if the care is not good. This is very very important.” (Lines 450 – 455)

The different roles that each family member has seemed to Hanaa as the cornerstone for her treatment and the children's rehabilitation, which impacted their development, as she frequently emphasised this by saying “really” repeatedly. She believed it was her obligation to encourage family participation so that all members could share the responsibility of care, understand the child's illness and the nature of the treatment and dispel any misconceptions or stigma around disability.

Looking at disability and how it is viewed in the Saudi culture, it was evident that there was a negative stigma related to it, such as the dehumanisation of the children and a feeling of

sympathy towards them. Hanaa strongly believed that this stigma was reflected in the parent's reaction to the disability and childcare, which seemed to be an upsetting matter to her, as she sounded annoyed.

“You know.. what they are doing is “oh this poor child”. I mean he is very like, he is just an object to sympathise with, he is not a person, he is not a human being, he is just an object.” (Lines 230 – 234)

The negative image of the child with a disability, being an object rather than a human, was against what Hanaa believed in as she expressed her opposition to the categorisations imposed by cultures, both Saudi and Indian. Rather, Hanaa viewed these children as human beings with some additional requirements and care and felt that parents and family members should be aware of this.

“This is not only here but even in India, what I felt is that this categorising... they are categorising those with special needs.” (Lines 495 – 497)

In Hanaa's opinion, these stigmas were reflected not only in how parents perceived disability but also in how children viewed themselves, which affected their self-esteem. As she described, children with disabilities faced feelings of isolation, loneliness and restriction as a result of their physical disabilities, which adversely affected their psychological well-being.

“I know this boy very well because he has low self-esteem. He’s always saying “I am poor, I cannot walk, I cannot stand.” Maybe he hears it from a family member or he is hearing it from the school, so I do not know. I need to send this child to a psychologist and get his confidence to improve.” (Lines 939 – 944)

She felt that her role was to help children overcome the negative self-reflection they were experiencing. By involving children in their treatment plan, considering their goals and believing in their abilities, she believed that children would be empowered and gain confidence as a result of their involvement.

“We all talk about parents or caregivers, and we never underestimate their power, the children's power itself... we have to tell them “you could do this one so ask the mother (do it for me this time)”, but you, you... he is still young, but still I mean if you give that confidence and motivation, some will.” (Lines 922 – 927)

Furthermore, she believed that integrating children with disabilities into their community and treating them like normal humans enhanced the children's self-esteem and empowerment.

“We really.... like other western countries, like they have schools, and even in India I see that mmm... they are not separated like a centre or a special school; they are integrated with the community, with other schools, so each school is providing the physical therapies and whatever, so we are at least going for at least an assistance of physiotherapy. Like us, we can go to their school, so at the same time they are getting so after they finish the school they do not need to be separated and then come to get the treatment, you know, they are human beings.” (Lines 901 – 912)

Saudi society's stigma of disability plays an important role in the rehabilitation of the child, as it affects the child's self-image and confidence. Hanna viewed stigmatising children as an unacceptable act that affected parents' knowledge and awareness of disabilities as well as their role in communication and collaboration with therapists.

Hanaa considered communication and collaboration vital elements of care that assisted her in understanding the parents' social and financial circumstances.

“So it is one way we understand the social or family situation is like that; some maybe they do not have money to buy whatever I am requesting them to.” (Lines 693-695)

In some instances, Hanaa also referred to communication as “an interference” that disrupted her clinical practice. Initially, Hanaa appeared hesitant when answering the question, but soon she spoke openly and expressed her dissatisfaction with the interference, where parents questioned her practice and compared her with other therapists.

“Ah.... you know sometimes... mmm.... it is sure it is important, but why I say like all this my discussions... ah... the parents are attending with us, sometimes it is disturbing honestly, sometimes because in between they are interfering “no this other therapists are not doing this way”... ah... “why are you doing this way? No, no, no I want you to do the same like other therapists”.” (Lines 619 – 625)

Hanaa's response to these interferences seemed to reflect her irritation about the matter. Usually, she would respond to those interruptions by explaining to the parents that there are many ways to solve a single problem, and that is why she spent so much time in college and earned her degree.

“So in such situations... ah... what we are always saying is “you know for example if I want to stand on my knee extensors, I am learning different ways to

stand on my knee extensors”. That’s why I learn in college, I mean if there is only one exercise to improve my knee strength, of course I do not need to spend all these years in my college.” (Lines 624 – 633)

She believed that the negative interferences were due to the parents' lack of understanding of the child's condition, resulting in frustration, depression, and loss. This seemed to be a situation Hanaa frequently encountered during her clinical practice, and she seemed unhappy about it.

“Most of them do not know exactly the diagnosis even. Here the parents are asking us “What is the problem of my child?”, and also you know they are frustrated to know that their child is having some problem.” (Lines 293- 296)

Hanaa felt that this led the parents to a state of not being realistic and expecting too much from physiotherapy and from the treatment. Therefore, she valued honesty with parents in such situations. Nonetheless, she preferred to give truthful information more thoughtfully, without rushing, which reflects Hanaa’s sympathy and consideration towards the family.

“They should understand the reality so that they do not have over expectations, and also of course the truths are better in the first time. But in time they will understand, they will... ah... go with the flow. This is what I felt.” (Lines 613 – 616)

Communication and collaboration between the physiotherapist and parents were considered essential elements of care that ensured parents had a thorough understanding of the child's disability, thereby facilitating rehabilitation. However, the lack of knowledge and awareness was

identified as a barrier that prevented proper therapy from taking place, which caused Hanaa to feel responsible for her role as a parent educator.

Hanaa reflected on her practice during the interview and shared situations and concerns that she felt were barriers to providing services. Among these barriers were the time limitations for treating the child and the increased number of patients to treat, which led to an undesirable interruption in treatment.

“Because we are very busy, and we cannot serve as we wanted, you know. Like for example, we want to give a break for two months, but this break is sometimes reaching up to five months because of our patients’ number, so that is also a cause I felt.” (Lines 894 – 898)

The Centre's opening hours and timing were considered another barrier that Hanaa felt was interfering with the child's everyday life as it formed an additional burden on the child and family. She believed that getting the child after school was an exhausting process for the parents, leading to the child's absence and irregular sessions.

“Another barrier is this school timing or our Centre timing. It is the same, so they are tired in the morning from the school, coming here in the afternoon and having a session, they are saying that “it is difficult sometimes”. So they are postponing sometimes, and they are not getting this regular treatment.” (Lines 875 – 880)

In addition, Hanaa reported that transportation posed a significant barrier to care as services were not always accessible.

“Here the first problem is the transportation. The transportation means that we are giving them schedules maybe one o’clock, but they cannot come at that time because they have to finish school, and then they have to come through this traffic to reach the Centre.” (Lines 853 – 858)

This, from Hanaa’s point of view, was related to the culture and social norms held by some mothers, which prevented them from riding with someone they did not know or even driving themselves, though the government has recently allowed women to drive.

“Here the culture is “my husband does not allow me to ride with others, only me or my family members”. So this is the cultural barrier for transportation, and they are not looking at another alternative to come to the Centre.” (Lines 871 – 875)

Hanaa seemed very aware and mindful of these barriers affecting her practice and care as she suggested solutions whenever she discussed a barrier to care. These included having a mobile treatment for children whereby physiotherapists would go to the children in their natural environment to ensure the child's integration into society and overcome irregular therapies.

“I think we therapist should go to them, in like a mobile, not them come to us, so this is one way I feel is very good, the children home centred.” (Lines 917 – 919)

She expressed her wish to collaborate better with other centres and physiotherapists across the city to stay updated with the latest treatments and discuss the barriers to service provision that they all face in their practice. Hanaa emphasised the need for all therapists to respect their

profession and the care of children and not to compete with one another but instead to serve the child's best interests, reflecting the "unity in diversity" values instilled in her by her own culture.

“So it is important, and I think at least for a day, that every therapist should be drawn from whatever routine for one day to spend time with others we ourselves meet... at least the disciplines working similarly, like the paediatrics. All the pediatric physiotherapists should meet and share their ideas on, as you said, barriers or how to overcome barriers rather than competing with each other. Of course, we compete for existence.” (Lines 977 – 985)

5.2.2 Adam

❖ *Participant background*

Adam is a pediatric physiotherapist who had worked in the Department of Physiotherapy at Mulberry-street Hospital for 30 years and was one of the department’s developers at the time of the interview. He graduated with a diploma from one of the health institutes in a large city and then worked at Mulberry-street Hospital for two years. Following that, he decided to complete his bachelor's degree and had an internal scholarship to one of the universities in the capital city, where he obtained his degree. Upon completing his studies, he resumed work at Mulberry-street Hospital in the physiotherapy department. At the beginning of the interview, Adam showed strong gratitude for his religious background as he referred to himself as a normal Muslim who was maintaining his prayers and doing all the religious obligations that Muslims do.

❖ *Interview room description*

The interview was conducted in Adam's office and treatment room. The room had two doors, an external door for staff and patients to use and a door connected to the office of the head of the physiotherapy department. The room was spacious and had two desks for office work, two chairs, a treatment bed and a small window. Adam sat on his desk on my right-hand side facing the door while I sat at the other desk facing him with my back facing the door. The doors were closed, and all staff were informed that an interview was taking place. The recorder was placed on Adam's desk along with the research information sheet, interview guide and consent forms.

❖ *Adam's experience*

The experience Adam had with family-centred care for children with physical disabilities seemed unique as it reflected the strong religious bond he had and his strong faith. Adam's clinical approach and the way he provided services and supported parents were guided by his faith.

According to Adam, the mother is the primary caregiver for the child in a Saudi context, as she is more nurturing and involved with the child's life, carrying the responsibility of caring for the child. Nonetheless, he saw the father's caring role as minimal to earning money to support the family.

“The mother is more caring because she is always with the child with a disability. The father goes to work... goes out and comes back, but the mother is the one who is always... ah... I mean she stays with the child most of the time so she cares more. So they have the... ah... the priority in the care and follow-up.. the follow-up of the child's condition.” (Lines 250-256)

Adam described the role of parents as equal to his own as a physiotherapist rather than simply as "important", indicating that parents had a significant role in rehabilitation. Most of these responsibilities involved caring for the child at home and following the instructions of the physiotherapist. Due to time constraints and limited session numbers, Adam felt that the care

provided at the Center was insufficient to meet the child's needs; he, therefore, viewed the family's role at home as crucial.

“...that they practice the exercises at home... because, for example, two sessions a week or the exercises or the three sessions a week are not enough... so the role of the family at home is a must. I mean, for example, in the house, like in the day and in the night, like a package... they do the exercises with their children so the improvement continues... so their role is not less important than the role of the hospital.” (Lines 78-85)

Adam believed that siblings played an essential role in the rehabilitation of a child with a disability. He thought that the child's anxiety and lack of comfort could be exacerbated by the absence of his siblings, preventing him from administering the appropriate treatment. In addition, Adam regarded the child's fear and unfamiliarity as obstacles to his care.

“The normal child coming with his brother or sister, we make him sit in front of him, next to him, play with him and tries to distract him until he is adapting well” (Lines 120- 124)

“but I mean if the child with a disability is in tension,, afraid.. he will not give you ahhhh the treatment you wish..” (Lines 124-126)

Adam explained how a parent's involvement in a child's care can have a profound effect on the child's condition in both a positive and negative manner. In his view, a child's progress or regression indicates the level of care and attention given to him by his parents. Instead, he seemed to view parental involvement in rehabilitation as a form of cooperation, which he appreciated greatly.

“You can see it on the child’s condition if the parents are cooperative or not. With cooperative parents, the child will come with more flexible muscles and joints, if it was treated, but if he was left without exercises, he will not benefit, the tension is there, the spasticity is still there, and his joints are not moving.” (Lines 112- 117)

Adam's perception of the importance of family involvement in rehabilitation influenced his interpretation and definition of family-centred care. In his opinion, FCC is a service that is designed to integrate children with disabilities and their families in the same session. In Adam's view, this could serve as a source of motivation for children and their families, resulting in significant clinical outcomes.

“The parents gather in... ah... one place, and there is like group therapy or a group of families present, and the children are present, and this gives motivation and... ah... there is cooperation, collaboration from the families and from the patients, and honestly, it gives excellent results.” (Lines 58-62)

While Adam believed in the effectiveness of group therapy and such collaboration between parents, he felt restricted from applying it in his own clinical practice. His main concern was that group therapy could not take place as he desired due to the lack of treatment space and resources available, which he felt was disappointing.

“We do not have it... no... we try... we try here in the department, we try depending on the place and... ah... the available resources.” (Lines 64-66)

Adam went on to describe how sometimes the parents' refusal to participate in such practices made it difficult for him to conduct group therapy. It appeared that the characteristics of Saudi culture, the conservatism of the people and the desire to maintain their privacy all contributed to the rejection of group sessions by some parents, who preferred not to participate in such activities. Despite Adam's desire to conduct such treatment, this barrier was understandable and acceptable to him since he belonged to this culture.

“Some parents of course do not accept that, so they have individualised sessions. They do not feel comfortable... you know, Saudis and Saudi society wants the privacy. They are a bit conservative....” (Lines 68-71)

Despite his ambition, it appeared that Adam's desire for such treatment was constrained by the cultural barrier and the parents' unwillingness to accept such an approach, which might be attributed to their lack of education and awareness of physiotherapy.

According to Adam, some parents lacked knowledge about physiotherapy and had a negative image of it, mainly due to the perception that it was just a massage. In his tone, he seemed annoyed and saddened by this stigma as he condemned such wrong beliefs held by certain individuals.

*“Most of the parents come to physiotherapy thinking that it is only massage.”
(Lines 94-95)*

Adam considered the parents' lack of understanding as a form of ignorance which sometimes led to interruptions in treatment. He clearly resented such interference with his clinical practice and appeared upset about it when he expressed the following:

“When the child cries not because of pain... because of the place... the child is not familiar with the place, afraid... so they do not want us to continue the... ah... session. They take the child and hug him and they say “this is enough for today”.” (Lines 161-165)

Adam viewed the children's crying during the session, along with their fear of medical uniforms, as natural and understandable challenges that can detract from the smooth flow of the session. Indeed, he emphasised that the child's adaptation and familiarisation were considered a lengthy process that normally took time and seemed to accept it.

“Some of the children do not accept the place because they have previous experience... they were admitted before. Some have a phobia from the white lab coat, whether it was a nurse or a doctor, and even from the needles, and so on. So slowly, slowly until the child is familiar with the place and people and is accepting the surroundings. But at first, there will be resistance.” (Lines 268-274)

As Adam pointed out, other methods of education used by the hospital, such as providing brochures to patients, were helpful in spreading awareness. However, he stressed the importance of his role in clarifying misconceptions about his profession, something that he considered very important.

“The awareness is done through the media or brochures, education that is happening in the hospitals. Here we have an educational clinic that highlights the role of physiotherapy. The healthcare practitioner himself... clarifies ... ah... the negative image of physiotherapy. It is not only massage and that's it.” (Lines 287- 292)

The importance of parent awareness and education was evident throughout Adam's narrative as he emphasised it frequently. He believed that awareness could positively impact the child's improvement, the parent's commitment to the treatment, and him personally.

“So eventually whenever you (short pause) implement the importance of physiotherapy and its effective role in the care of the child with a disability, the child will improve, it will be beneficial, of course.” (Lines 102-105)

Adam felt isolated from the other medical staff when it came to working in tandem and collaborating. He wanted to feel like he and the other physiotherapists were part of the bigger medical team treating the child, and not like they were left out.

“We are not supposed to be isolated from the physician, the neuro physician; we all have a role as a whole team.” (Lines 191-193)

In his opinion, the collaboration between the parents, therapists, and other healthcare professionals was essential as it significantly affected the child's progress.

“Not only the collaboration between the physiotherapist and the parent but also with the physician treating the child. This is very important.” (Lines 189-191)

Though Adam recognised the positive effects of collaboration and communication on the child's condition and the parents' support, he seemed to play an indirect role in further assisting families. As Adam saw it, enabling parents to strengthen their faith in Allah was a form of

emotional support that he provided. Adam's approach to supporting parents reflected his strong faith and religious ties, which is evident from his quote below:

“They should have faith in Allah, and that there is nothing impossible with Allah’s will. With the exercises, with the care, things will turn good.” (Lines 312-314)

Moreover, he believed that encouraging parents to have strong faith and hope not only contributes to their emotional well-being but could also assist them in accepting their child's disability. According to Adam, faith, patience and perseverance for improvement are key motivators for parents to continue and remain committed to the desired treatment.

“They believe that this is destiny from Allah, and they welcome the situation, especially when the child improves... they get excited... they get excited and happy when they see their child instead of only rolling...now he rolls, he crawls, he sits. He couldn’t stand before, but now he stands. And eventually they continue, and they are happy with it.” (Lines 314-320)

Adam reflected on some barriers that he felt prevented him from delivering the desired treatment to children. For example, one of the challenges that affected Adam’s care and physiotherapy treatment was the parents' lack of understanding and being emotional or superefficient, such as the parent's reaction to the child’s crying and their interruption of the session.

“Yes, there is, for example, the emotion... parents with affectionate passion.” (Lines 260-261)

Adam expressed his desire for improvements in care and services, which he believed were necessary and useful for a child with a disability. As part of these amendments, functional therapy and intensive treatment was suggested to speed up the child's rehabilitation process.

“The functional therapy... this is very important to the children... how to practice in their daily life activities. I think this is what we are lacking and most of the hospitals do not have it. If it was provided, the child would benefit from it a lot. Or even if there are programmes available in some of the centres where the child comes from in the morning and stays until 3 pm. The programme is made for those with difficult cases. They can benefit from such services as well.”
(Lines 324-332)

5.2.3 Maya

❖ *Participant background*

Maya is a pediatric physiotherapist with 12 years of clinical experience who had worked in the Department of Physiotherapy at Whoville Hospital for nearly five years at the time of the interview. Maya used to work as a technician at one of the big rehabilitation centres in the kingdom before she completed her bachelor's degree and moved to the current city to work at this hospital.

❖ *Interview room description*

The interview was conducted at the department itself. The department was a small area divided into two areas and separated only by a curtain. The rehabilitation takes place in the larger size area while the smaller area is designated for physiotherapists to take their break, rest or even do

their work. The interview took place in the physiotherapists' area; it had two leather couches facing each other, and, in the middle, there was a small coffee table. The area had a big wardrobe, a working desk with a PC for therapists to use and a clothes hanger. I sat on the couch facing the wall while Maya sat on the other couch facing me and the other wall, which had mirrors. Since the other therapist had a patient during our interview time, the curtains were closed; the air-conditioning was turned on, and other staff members were informed that an interview was taking place so that no one would interrupt us. Before the start of the interview, I asked Maya if she was comfortable with the setting or if she would like us to find another place to talk. Maya stated she was okay with the situation, preferred to stay in the department and was happy to do the interview there.

❖ *Maya's experience*

Maya's experience was different as she lacked an understanding of what FCC meant. Despite this, she appeared to highly value the family's role in the child's life and to respect their presence and participation in the treatment, as she described the family's role as "strong."

"So yes, they have a role, an important role for sure... very important and strong role." (Lines 72-73)

She appeared to be welcoming of the presence of different family members as she went on to describe the family members in terms of mother, father, and siblings, all of whom could have a role in supporting the rehabilitation of a child within the family.

“...no mother, father and siblings... we ask the mother “Do you have somebody at home that can help you? Do the exercises with you?”... “you are welcome to bring them with you to the session, let us teach them.”” (Lines 77- 80)

Despite Maya's belief that the involvement and presence of all family members were crucial for the rehabilitation of the child, she described her practice as primarily focused on the mother. To Maya, the mother was understood as the primary caregiver of the child with a disability, to whom she directed her attention.

“We focus mostly on the mother.” (Line 169)

She believed that the mother's role lay in the child's assessment, during the session and at home. To Maya, mothers were considered the primary source of information related to the child's condition, which helped her with the assessment and treatment plan.

“First of all, when the mother comes, you take from her the assessment and all the information you need in the assessment.” (Lines 45-47)

In fact, Maya viewed the mother's main role as to do the exercises for the affected child at home; thus, her understanding of exercise seemed to be Maya's priority when providing treatment. According to her, the mother's role as a caregiver can significantly affect a child's condition and development, either positively or negatively.

“...their importance... the importance of the exercises, if the mother did not repeat, if there is not a lot of repetitions during the day, there will be no, no

results. There must be repetition throughout the day, there must be sessions with the child, but the mothers who do not ... it is obvious, obvious... the mothers who do not do anything... do nothing when they go home, the child does not improve or progress.” (Lines 66-72)

Maya implied that the fathers' participation was limited and infrequent. She used her previous workplace as an example, where she was able to include both parents in the treatment planning process, but she did not feel able to do so at the current facility. Maya felt a limitation due to the lack of a separate clinic or department, which prevented the fathers from participating in the therapy session.

“...but ah... here I mean we did not have a clinic so when the mother comes, she enters alone without the father.” (Lines 92-94)

In light of the father's restricted entry and limited participation in rehabilitation, the mother played an important role in communicating information about the child's condition to him, indirectly involving him in treatment. Nonetheless, Maya appeared to respect the mother's wish to meet the father as well as involve him directly if she so desired, which reflected Maya's flexibility and willingness to accommodate the mother's wishes.

“The mother tells him, and if she wished for us to see the father, we would meet him. I mean... ah... we do not mind.” (Lines 96-97)

Maya viewed her educational role as crucial, particularly with those siblings who were jealous of the affected child because they received more parental attention. As a physiotherapist, she saw

herself as playing an important role in assisting children without disabilities in comprehending their sibling's condition and the necessary care required.

“Some of the siblings do not accept their affected brother, or they see them getting extra care from the mother or the father, so we bring them and explain to them “he will walk, he will improve, he will be better.” (Lines 105-109)

In addition, Maya felt she played an essential role in educating and guiding parents when they first arrived in the clinic with their children. This responsibility included keeping the mother informed regarding the child's treatment, teaching her the desired exercises, and ensuring that she followed them correctly. In Maya's view, empowerment was a form of collaboration between her and the parents, which formed an important part of her daily practice.

“I normally come and bring the mother and the child and we sit together... ah... I give... ah... the first exercises. I give it to the mother and tell her the benefits of this exercise, and then I do it many times, many times, and then I let the mother do it in front of me so that she does it correctly.” (Lines 47-52)

Maya's practice seemed to be influenced by the mother's understanding of the exercises and the parent's acceptance of the treatment and physiotherapy itself. She described how she faced mothers who did not believe in physiotherapy and did not accept it, which she felt was hard to deal with. In Maya's view, this barrier hindered the provision of her services and practice; however, she explained how she attempted to overcome it by educating mothers and encouraging them to inform themselves about physiotherapy.

“The parents' acceptance... it is something difficult, but I must bring the mother twice... it is very difficult. There are some parents who are denying; they say “We do not believe in physiotherapy”. So I bring her to the first session, and I bring with her a mother whose child has improved. In the second session, we tell her “Please come and see and try yourself”.” (Line 241-247)

In the role of family advocate, Maya promoted communication and information sharing between siblings and parents so that they were aware of the child's disability and rehabilitation. In the course of the treatment, Maya seemed to make every effort to communicate with the mothers, explaining exercises and following up with them, even outside of her working hours, where communication was viewed as “a must”. As part of her communication strategy, Maya used various communication methods, such as WhatsApp, sending videos and pictures and calling parents to follow up on the child, demonstrating her affection, concern and desire for mothers to understand the physiotherapy exercises.

“...for example, I explained to the mother the exercise and gave her 4 exercises in this session. I told her “You did not know?”, then I bring a paper and write down the exercises and explain the exercises to her. So the communication is a must. “If you do not understand, it's okay, you can send me WhatsApp” and explain things to them again. We send videos, we send pictures. So communication is really important all the time - during the day or we call them. Here in the department we have a policy where if for example the patient was absent for two or three sessions, we would follow-up with her and call her “Where are you, why did you not come?”, so we ask for the reasons.” (Lines 116-127)

Maya seemed to understand communication as a two-way process, in which she taught parents the exercises and provided explanations while also listening to their concerns and requests. She

went on to describe some instances in which parents objected to certain treatments or a specific therapist. Maya described it as "normal", indicating her openness and acceptance of such objections.

“Yes, this is normal; we see a lot of cases.” (Line 255)

Despite Maya's belief that parents should make the primary decisions regarding the child's rehabilitation, she felt it was important to be autonomous in her decision-making. In her description, Maya explained how she would first explain to the parents how the treatment of a child with a disability may vary from one therapist to another and would encourage parents to first see the benefits before making any further decisions.

“I tell her that each one of us has his own way of dealing, especially with paediatrics, not like the adults. The way of exercises differs from one specialist to the other. So I tell her “her way differs from my way” ... “This time I did you something different, you repeat it and see if it was beneficial”. We are physiotherapy .. if you do any exercise more or less than requested, the patient will not die, it's okay to increase the number of exercises.” (Lines 257-264)

As for family-centred care, Maya defined it according to what she had heard and not as she perceived it. FCC was defined as a support service provided to families to help them understand the condition of their children and to assist them as needed; however, Maya believed that it did not exist in governmental hospitals.

“I heard that they call the mother, the father and the siblings, and they support them like “you have a child with disability and he cannot walk”... like this...

ah... they explain to them for example “he walks or he might not walk”. If he needs support at home, they provide it to them, but here we do not have this, we do not have it.” (Lines 178-183)

Maya described how FCC differed from her practice and the support she provided, pointing out that the support she provided was a natural process of giving, which she fully accepted.

“In family-centred care you need to provide them support in this and that, but we do not; it comes with the flow.” (Lines 191-193)

“I mean this thing we are providing it from ourselves humanly. It is not dictated on us, but humanly we provide it from ourselves.” (Lines 183-187)

Although Maya made every effort to support families and children in fulfilling their needs and desires, she felt that some barriers prevented her from doing so. She considered the physician's cooperation in providing the referral helpful, but she was unsatisfied with the level of communication and collaboration she experienced. For Maya, the collaboration between herself and the other medical personnel treating the child was crucial to the success of her rehabilitation programme.

“There is a collaboration with the physicians, but basically it is only for the referral. If we needed something or we suggested something to the mother, we could talk to the doctor... “we have suggested this and that, please refer the child to this place or to that place”, so collaboration is important, but we do not have... they, they do not give us the authority to do so.” (Lines 209-214)

Maya described how she felt that her limited authority to refer the child to the right place for help directly was a barrier to providing proper care and support at the time she desired. This seemed an upsetting issue to Maya that prohibited her from fulfilling her role as a physiotherapist and limited her autonomy in the child's treatment. She sounded offended when saying the following.

“You mean the limited authority? Look, if I could refer the mother immediately without going back to the doctor, I refer her to occupational therapy and like this without this bureaucracy in referral. I mean it will be faster and better instead of the bureaucracy in referral... “No go back to the doctor and he will refer you”. We are therapists. Unlike the physicians, we cannot refer.” (Lines 224- 230)

Furthermore, Maya stated that the lack of a large department as well as a shortage of treatment devices were significant impediments to giving effective care.

“We do not have a department... big department in the hospital. We do not have a lot of devices. We do not have a treadmill. We do not have things. There are no devices provided.” (Lines 234-237)

She felt that her practice and the pediatric rehabilitation programmes in her current city were generally delayed and wished that these barriers could be overcome in order for physiotherapy services to be improved.

“They develop us, make the workshops less expensive, and they open a big department and provide all the devices and things needed and have more facilities.” (Lines 272-274)

5.2.4 Rasha

❖ *Participant background*

Rasha is a physiotherapist who had worked in the Department of Physiotherapy at Roover Hospital for almost two years at the time of the interview. Rasha was a 37-year-old therapist with 15 years of clinical experience, working mainly with different cases, adults and paediatrics, in the last three years. She worked as a technician for 11 years, at two other hospitals in one of the cities in the Kingdom, before completing her bachelor’s degree and moving to work at Roover Hospital as a pediatric physiotherapist.

❖ *Interview room description*

The interview was conducted during Rasha’s lunch break as she felt it was the most suitable time for her because she did not have patients then. The interview took place in the therapist’s treatment room, which was vacant, and no patients were there. The treatment room had no windows but cartoon drawings on all four walls. There was a treatment mat, a spider cage (treatment tool), stairs used in gait training, a small tv, and a working desk with two stools for the use of physiotherapists or parents. At the beginning of the interview, we sat facing each other, facing walls, and the recorder was placed in the middle. During the interview, we had to change the room and move to a quieter room. We moved to a big treatment room with five treatment cubicles, with beds only, and each cube was closed by a curtain. Since no one was

there during the interview, we sat in one of the cubicles. The curtain was open, I was facing the wall while Rasha was facing the curtains, and the recorder was placed on the treatment bed.

❖ *Rasha's experience*

Rasha showed consideration towards parents as she explained how their goals and desires were perceived as guidance for her clinical practice and decisions and was a practice she always followed in rehabilitation.

“Also I care about the main goals, and I work on the parent's chief complaint. If one comes to me telling me “My child is not crawling”, I will start to work and focus on the mother's main goal, and based on that I will continue the session with the child.” (Lines 81-86)

Not only did Rasha care about the parents' requests but she also considered the parent's acceptance of her as a physiotherapist to be a very important aspect of care that determined the child's commitment and continuity of treatment with her.

“From the first session, the patient and parents' acceptance are important to whether you should continue with the child”. (Lines 440-442)

Additionally, the importance of building rapport and maintaining good communication with a child with a disability and ensuring his/her psychological relief and acceptance towards her and the treatment was Rasha's clinical focus. She showed understanding and acceptance towards the child's adaptation process, which can be lengthy in nature and could affect rehabilitation.

“I feel like it is also really important even with the babies themselves... there must be communication. I mean, it is not necessary that the child from the first session accepts me. I could stay with him for a while until acceptance happens.”
(Lines 541-545)

Rasha appeared attentive to the parent's and children's acceptance, so I was curious about her comprehension of family-centred care, what it meant to her, and how she experienced it. Rasha stated that she had never heard of the concept but assumed it was a practice concerned with the child's family. She regarded FCC as a practice that provided parents with guidance, support, and education that was distinct from her clinical services.

“I feel that it is something that happens if they have a baby who has a problem. Maybe this thing is concerning the family. I mean, like they give them education, psychology, sessions... ah... maybe they show them how to deal with the child at home. I feel that it cares about the family around the child more than the patient himself.” (Lines 696- 701).

She continued by describing the difference between her current practice and FCC. According to Rasha, in the former, she would concentrate her efforts and attention on the child the majority of the time, while in the latter, care is primarily directed toward the child's family.

“I mean, here if we talk about the sessions, 80% I focus on treating the patient, and 20% I focus on the families themselves. Like I feel that in this concept you focus more on the family...we are more patient-centred.” (Lines 705- 708)

Though FCC was viewed as a different practice, Rasha showed a good understanding of what she thought it meant and went on to describe the different roles of care that the family played in a child's rehabilitation. It was evident from Rasha's narrative that the fathers played an essential role in the rehabilitation and care of their child, as she admitted to accepting their presence in the sessions. She described how their involvement in the child's care was limited to their attendance with the child and limited to the child's attachment to the father. This caused fathers to play a minimal role in the child's rehabilitation.

“Yes, but it depends. If the child came with his father, yes, we could allow him in. There are some children who are attached to their fathers more; even the mother would say “the child will remain silent with his dad”, so we bring the father and the child in and we do the sessions.” (Lines 461-465)

In some circumstances, fathers were viewed as helpers to Rasha, who played an important role in calming and comforting the distressed mother through supporting her and helping her understand the child's condition.

“The mother cannot stop crying since she came into the clinic. She just cries, cries, cries. ... ah... We tried to calm her down. And then when the father came in, I told him “Your son is really fine, thanks to Allah, he does not have a high muscle tone, but he has a small...” he started taking the syringes... the stereotype for the hemiparesis and weakness... So I told the father “Your son is fine” ... and the child wanted his father to give him the exercises, so the father started to shush the mother telling her “shush” ... ah... When she starts to talk, he tells her “shush and listen to the doctor and what she is telling you, shush, do what the doctor is telling you, shush”.” (Lines 470-481)

In other instances, Rasha felt that fathers were better than the mothers at doing the exercises, and thus she viewed their roles and involvement in rehabilitation as something positive that helped in the child's improvement and appeared to be pleased about it.

“...and really we find that the father is really caring about his child and doing him the exercise better than the mother.” (Lines 466-468)

Rasha felt that the role of siblings was not only to motivate the affected child but also to help elevate the mother's mood. Indeed, she appeared to strongly support the vital roles of the siblings and father in sharing the responsibility of care with the depressed mother, supporting her so that she does not feel alone.

“...like this depression case today. I told the father “do not rely on the mother only.. she is psychologically down... bring me your daughters because everyone must work, everyone”. He said “okay, I will bring them in the morning and let them miss school once”. So I told him “Bring them because I need them, the mother is not the only one to take care of the child, because if she feels that she's alone, she will become depressed... everyone should work with her”.” (Lines 498- 506)

Rasha felt that all family members had an essential role in the child's rehabilitation, including the mother, father and siblings. She considered both parent to be partners rather than parents and that their cooperation was crucial for the rehabilitation of the child, reflecting the significance of their engagement to her.

“The families must be cooperative with us; they have to work at home.” (Lines 87-88)

Additionally, she emphasised how the involvement of family can be of great value to families themselves as they can witness realistic improvements personally, which Rasha felt can help motivate them and make parents comply with the child’s treatment.

“I mean like despite the fact that they do the same sessions we follow at home, ah... they also see that they are working on their children and seeing improvement. Like for example, the mother of T..... if she did not see improvement in her child, she wouldn’t have continued the physiotherapy sessions.” (Lines 228-233)

Despite her conviction that each family member played a vital role in the rehabilitation process, including the father and siblings, Rasha faced some barriers and challenges related to involvement, which affected the rehabilitation. A significant challenge was the harmful influence of others on parents as well as the stigma attached to disabilities, which affected parents' opinions and views regarding physiotherapy. As Rasha explained, such inconsiderate attitudes by others have caused parents to disbelieve physiotherapy and have resulted in their depression, which was clearly an issue that irritated her since her tone reflected her displeasure at these interferences.

“Another thing is the environment around them, like this mother who had depression... from what? Every time she goes to any place they tell her “Your daughter is crazy. Your daughter does not move. When will your daughter move? She’s 3 years old. Your daughter does not talk.” The same thing happened with the mother of T. She faced this challenge at the beginning. She

says, *“when I go out they tell me your son has and has and has....”* (Lines 301-308)

“...so their views would change slightly because the people around them make them feel down, and there are some people around them who suggest treatment... they invent therapies. Like they tell them “My daughter was like your child, and I took her to someone who clicked her back” or “oh my child was like this, so I bought him oil and massaged him, and my child is fine”. This is what they believe in.” (Lines 316- 323)

In fact, Rasha sensed that the interference of others around the family, their suggestion of treatments, the negative comments about the child’s disability and the parent’s lack of faith led families to seek alternative practices such as traditional therapy rather than Physiotherapy.

“...traditional medicine... they believe in traditional medicine more than the physiotherapy. But we have to change the way they think.” (Lines 327- 329)

She believed that parents' trust in these practices might be attributable to a lack of awareness and understanding regarding the significance of physiotherapy, resulting in their ignorance and erroneous judgments. According to Rasha, parents' educational level significantly influenced their views, opinions, and beliefs regarding a particular treatment, causing them to make poor choices.

“Yes, of course, this is one of the things that differs, and I felt that it has a role. I mean, the mother that came to me today... ah... I believe she is in the secondary... she has secondary school education... and she is very depressed and does not acknowledge something called physiotherapy. She is from those

who says “I might take my son to a nanny, a masseuse and treat him better than physiotherapy” like she does not believe in physiotherapy .” (Lines 196- 204)

Therefore, she felt that she played a vital role as a physiotherapist in clarifying and correcting the way parents sometimes think about physiotherapy by empowering them to face such negative influences and providing them with the appropriate explanation and guidance.

““Do not listen to anyone around you; they do not know the condition and they do not know the child, how he came to be like this and what problems he faced during birth.” So these are also some of the important things that we tell the patients.” (Lines 312-315)

Rasha highlighted another barrier that affected the child’s improvement and rehabilitation, which was the overprotection of the child by the parents. The over protectiveness was believed to be caused by the mother’s fear and lack of awareness, which could lead to the child’s regression.

“The protection around the child prevented her from walking... and she was depending on it.” (Lines 428- 430)

In Rasha's opinion, the mother's psychological state may be a barrier to the child's rehabilitation, resulting in either positive or negative outcomes. She stressed the importance of ensuring the mother's well-being since maternal depression can easily develop during rehabilitation. As Rasha explained, the lack of realism and the false hope of some mothers, as well as the frequent changes of therapists, contributed to maternal depression and anxiety that affected the mother's

acceptance of physiotherapy. This seemed to be disturbing to Rasha as she expressed how she would constantly seek help from other family members to support the mother psychologically.

“To me psychology is very important for the families. Today a mother came to me. She had only one session, and she became depressed... ah... and she does not want to continue any physiotherapy. She said “I feel that the physiotherapy has no importance”, so we tried to support her, and we brought the father and the girls, and we did sessions with them, and the girl (patient) was very good. She can walk, but the mother’s psychology affected the baby.” (Lines 88- 93)

Although Rasha considered the family to be helpful in supporting the mother, she noted that sometimes convincing them to accept physiotherapy can be challenging. She believed it was her responsibility to enlighten parents about the benefits of physiotherapy and to ensure that they adhered to the treatment regularly.

“But maybe, like you said in the beginning, the families, those on their own, are a problem, like if he is not convinced that “I will bring my child every session”, I’m... I mean, these are one of the hard things that we face, and I consider it a challenge. So we have to convince the parents first of all.” (Lines 715- 720)

In addition, the father’s lack of knowledge and involvement seemed to be a stressful challenge for Rasha as she struggled to deal with the negative stigma about disability that some fathers had. She sounded displeased by this as she felt that these stigmas had a direct negative effect on the child’s care, leading to treatment termination in some instances.

“The father of the child was refusing to give him physiotherapy. He told the mother “Do not exhaust me and exhaust yourself, your child will not walk and will not stand”. The father was working at the court. I mean, he is not ignorant. He was a judge in the court. So he told the mother “Your child will not walk and there is no use from physical therapy, do not waste my time and your time”.”
(Lines 382-388)

Rasha felt disappointed by such views and was sad about the child’s regressed condition. She seemed to blame the parents for the child’s deteriorating condition as she sensed that the lack of concern and care of the parents, and their negligence to do the child’s exercises at home properly, had led the child to the condition he is at, which she sounded displeased about.

“And understand that what the child has reached to was because of the negligence and because you did not give the child early intervention, physiotherapy.” (Lines 292-294)

Despite the challenges and barriers that Rasha faced in her clinical practice, she acknowledged the different roles she played in overcoming such difficulties. This might suggest that Rasha viewed her role in rehabilitating children with disabilities to be very important, a cornerstone of rehabilitation. Rasha spoke about her responsibility towards her profession and the families she worked with, such as educating families, increasing their awareness about the profession and correcting their views.

“So I explain to them the type of exercise. I do not just work like this and that’s it... no... that’s how they know what physiotherapy is and know its importance and how to apply in on their children.” (Lines 248-251)

Rasha strongly believed that the only way to increase the father's awareness of the importance of physiotherapy was by sharing with him cases of other children with conditions similar to his child's where the child had experienced real improvements. For her, using other cases was considered a way that helped her to increase the father's awareness and understanding of the importance of physiotherapy.

“So we could give him examples and let him see... or we have to increase their awareness.” (Lines 296-297)

Being realistic and honest was also viewed by Rasha as an essential aspect of her role as a physiotherapist, which she perceived to be founded on honesty. The fact that she referred to these unrealistic expectations as *"daydream"* demonstrates that she was concerned with not giving the mother false optimism but rather presenting her with a realistic future outlook and outcomes. Rasha believed that being realistic with the mother helps alleviate the mother's depression, increasing her awareness and positively impacting the child's care and treatment compliance.

“We have to give them something realistic, I mean I do not depress them or give them a daydream; we have to be realistic with the parents that the patient should be like this.” (Lines 97- 100)

Despite her efforts to help families out with the support they needed financially, Rasha in some instances felt that the families exploited the financial support provided personally by her and other staff members. Such a negative situation has prevented her from fully meeting the support role she wished to offer as a therapist.

“In the past, we used to collect money and pay for simple things like a wheelchair that cost 1200 riyals. We collected money to buy it, but now we can’t. It is really hard because everyone comes to the physiotherapy so we buy them stuff.” (Lines 656- 661)

Rasha described how collaboration between her and other therapists had a positive impact on her as well as on the children she was working with. She emphasised the importance of children seeing each other in sessions and motivating one another.

“I feel that when other children see this child doing exercises so this will give them more motivation. When we work as a group, it will be very nice.” (Lines 597-599)

Rasha considered working in groups or having group sessions to be very important in rehabilitation and viewed it as something enjoyable that has a significant effect on the mothers, children, and her personally.

“The mothers were very happy, and I felt that there is a big effect. In addition to that, the mothers used to laugh and make fun of themselves when a mother’s child kicks her or pulls her scarf. It was a very nice and fun session.” (Lines 615- 619)

Rasha showed personal attachment towards group-session as she felt sad for not continuing them. She explained how some barriers had affected the provision of such sessions, like not having her own place and limited space, and she sounded unhappy about it.

“I was on my own, so I was able to do, but now because we are a lot, we do not have enough space, we do not have a space to do a group session.” (Lines 634-637)

In her statement, Rasha expressed her desire for a larger working area and additional tools to be used in the child's treatment as these are thought to impact upon the child's rehabilitation. Additionally, she expressed her intention and clinical direction towards promoting family education, group sessions and nannies' education, which she considered important aspects of rehabilitation.

“We need a bigger Centre... (laughs)... we need a bigger place, we need... ah... staff. I guess we are enough and suitable for the place... ah... there is a shortage in some of the tools needed, which affects the physiotherapy.” (Lines 731- 734)

“As I told you about our future plan... we will do education for the families and mothers... ah... we will do group therapy like before, for the pedia.... and also for the caregiver who is giving the care. There are some children who come with their nannies, so we have to teach them. So this is the plan and the things we intend to do.” (Lines 738- 743)

5.3 Mothers' Idiographic Experiences

5.3.1 Wed

❖ *Participant background*

Wed is a 39 years old woman and a mother of 6 children, including her child Ahmad. Wed had completed her high school diploma and was a housewife who did not work in paid employment. Her child, Ahmad, had diplegic CP and had been treated at Salamago Centre for the previous seven years since the age of 9 months.

❖ *Interview room description*

The interview was conducted in one of the main treatment rooms in the department, which was vacant during the interview. The room was spacious, with two doors at each end and a couple of windows. It was fully equipped with two treatment beds, a treadmill between the two beds, a long treatment mat facing the bed, two mirrors at the far ends of the room, a bench, stairs for the children to climb, a ladder used for treatment and four stools used by the physiotherapists and parents. The beds and treadmill were on one side of the room, while all the other stuff was on the opposite side. The mother came into the room with a baby stroller and her toddler while Ahmad had treatment with his physiotherapist. I sat on the bench, facing the wall, while the mother sat next to me, facing the door. The recorder was placed on the bench between us.

❖ *Wed's experience*

Overall, Wed's experience with Ahmad's rehabilitation seemed negative as she had encountered difficulties with his care at home and with the physiotherapy provided at the Centre. It appeared that her involvement in her son's rehabilitation treatment was minimal, as she believed that her role was limited to answering the physiotherapist's follow-up questions and following the exercise instructions.

“When he finishes the suite, they would say “how did your child improve, what improvement did you see in him?”, and after the operation, they would ask “what are the things improved in the house, did he start to stand, how is the walking?” and like this they ask me, and I answer.” (Lines 67- 72)

Additionally, Wed acknowledged her role at home; it is the mother's responsibility to care for the child with a disability and all other members of the family. Wed understood that it was her responsibility to care for and exercise the child, but she believed that her time constraints and other family obligations prevented her from fulfilling this obligation. This overwhelming task occasionally impeded Wed's ability to perform physiotherapy exercises for her son, and it appeared to cause her great distress.

“My role as a mother is to care, but there is no time. I mean, you know the family connection with your children, there is no time to give him physiotherapy or anything.” (Lines 83- 85)

Furthermore, her son's other obligations, like studying and eating along with his lifestyle, made it very challenging on Wed to conduct the exercises. She struggled with prioritising the tasks and felt restricted by the available time she had to fit in the exercises in her son's schedule.

“I mean, he comes from the school, studies and everything and he sleeps early, so I can't give him physiotherapy.” (Lines 86- 87)

Feelings of loneliness and not having support were experienced by Wed as the father and other siblings were not helping her at home. This has forced Wed to carry the full responsibility of care alone.

“Yes me... my biggest child is 12 years. What can he do? And my husband goes to work and comes back at 3:00 pm. He barely can hold the children and help them with their studies. So there is no one taking care of him but me.” (Lines 244- 247)

In addition, as implied by Wed, the father's involvement in the child's treatment at the rehabilitation centre was nonexistent. The father's employment caused him to get exhausted and left him with no time to care for the child, as reflected by her use of the word "barely" to describe the difficulty of his situation. Wed viewed this as a barrier to the father's participation in the child's rehabilitation.

“His father? No, he cannot because he is too busy in his work and he comes home so tired and can't hold him.” (Lines 252- 253)

Being overwhelmed by the increased burden of care for a child with a disability and having other responsibilities at home have led mothers like Wed to lose their essential self-care, like simply having breakfast in the morning. Wed inferred how a simple task like this was impossible due to

her motherly responsibilities, which she felt was irritating as she did not receive the support, she required to carry this burden.

“We have breakfast in the morning. We barely get them dressed or we do breakfast or we do what? Where is the support? Where is the support of these poor children? We did not see anything..” (Lines 307- 309)

While Wed was tasked with performing physiotherapy for her child, she did the best she could to fulfil the child's needs. However, she felt that the Centre was obliged to support her son's treatment by providing physiotherapy sessions since they were privileged to have such equipment available. Not having the right device at home seemed to Wed to be another barrier to not carrying out her son's exercises at home.

“So the centre is supposed to be responsible. I give him treatment, but I don't have the devices like here in the Centre. The Centre has all the equipment, so they are supposed to help the child.” (Lines 87- 91)

Furthermore, Wed lacked the self-confidence to do the child's treatment at home and viewed herself as a mother only who did not have the experience to do physiotherapy. On the other hand, she considered the physiotherapists to be the experts, knowing right from wrong, who Wed depended and relied on.

“Okay I do him massage, but I'm his mother, not like the expert who knows physiotherapy and knows what is right and what is not. That's the problem with the Centre.” (Lines 238- 241)

Wed felt that she needed guidance and support regarding physiotherapy as she viewed it as her hope for the child's improvement and considered it the only clinical treatment for her son's illness, and she believed no other treatments were beneficial.

“Because the treatment for these hypoxia cases need physiotherapy only; there is no other treatment but physiotherapy.” (Lines 103- 105)

Wed recognised the positive role that physiotherapy played in her son's improvement as she highlighted how it had previously changed the child's condition for the better. This apparently was reflected in Wed's psychological status as she felt pleased and grateful for the child's improvement and physiotherapy.

“The child has improved better than before, thanks to Allah. He improved with the physiotherapy.” (Lines 126- 127)

In addition, she drew attention to the absence of collaboration and communication between therapists as this partnership was not acknowledged by all therapists despite its importance. According to her, its significance was in managing her son's calendar so that his appointments did not overlap or conflict.

“Yes, yes, very important... in the schedules so they know when will each other have the sessions. So yes, there is collaboration; it is important.” (Lines 190- 192)

Moreover, Wed stressed the importance of collaboration between her and therapists, particularly Saudi therapists. Nevertheless, she felt unhappy and upset when several Saudi therapists were removed from the Centre for unknown reasons.

“They removed three or four Saudi physiotherapists because they are looking for people with cheaper salaries. Okay, they are Saudi girls who are really good, they are so cooperative with mothers.” (Lines 318- 322)

She also seemed to be not fully satisfied with the services, as she desired more intensive therapy.

*“The child is better than before, but still we want intensive physiotherapy.”
(Lines 128- 129)*

Wed demanded more improvements in services, appointments and information about her child. She felt that the information concerning her son was limited to general information about possible outcomes for the child and viewed it as “nothing”, reflecting her underestimation of the information offered.

*“There was nothing. They just told me “the child will improve and will walk”.”
(Lines 148- 149)*

Being regularly seen by a physician seemed a source of information and reassurance to Wed as it seemed to help her understand the updates on her child’s condition and the reasons for the refusal to offer her son the treatment she desired.

“I want a doctor to see him regularly whenever he comes to the Centre. He sees how the operation is. He sees the x-ray for the pelvis.” (Lines 134- 136)

Wed expressed concerns about the child’s treatment at the Centre, which was perceived as being a lengthy process happening by chance, with irregular appointments and intermitted treatment. She appeared very unhappy about it.

“Here they do not call you always, only every 6 months, and it is by chance. If you answer or do not answer, they find another child. They take quite some time till they call, until your turn comes... 6 months, 4 months... they call you... 3 weeks, and that’s it! They forget about you until after 6 months they tell you to come again. This is not a Centre.” (Lines 105- 111)

The feeling of being forgotten about was sensed by Wed as she struggled with the delayed appointments and sessions, which was so displeasing to her. Wed showed constant initiative to contact the Centre and follow up on the updates with the delayed appointment; however, she was always turned down. Wed was told that the delayed treatments were caused by the therapist’s full schedules, which was attributed to the high demand on them due to not having many therapists at the Centre.

“Yes I call and they say “the schedule is still full.. the schedule is full”, so that’s why.” (Lines 117- 118)

Although she seemed to understand the reason behind these delays, Wed had a conflict of emotions as she was very disturbed by such interruptions and blamed the responsibility of the regression in her child's condition on these delays.

"I ask "when is the physiotherapy?" and they reply "still we will see the schedules". Now he has regressed as if he did not benefit from the suite." (Lines 203- 205)

She apparently was unhappy with the interruptions in services, which was reflected in her upset tone; nevertheless, Wed seemed unable to seek rehabilitation services at other centres. She felt that they "as a family" were restricted by their financial status, which did not allow them to afford alternatives, and this seemed to be something that they had no control over.

"Okay my husband cannot afford it and he does not have enough money for our child. If I had money, I would not wait for you. I would take him to another centre. But the other centres would take 3000 riyals." (Lines 232- 235)

The fact that the centres were pricey and unaffordable was not the only factor preventing Wed and her husband from taking their child to other treatment centres. The added responsibility of caring for a child with a disability and other living expenses and caring for other children has limited their capacities.

"Okay, what about the rent? How much does it cost? And expenses? And how much the children are costing?" (Lines 232- 237)

These restricting circumstances had forced Wed to keep her son at home and be left without treatment until an appointment becomes available, which seemed very difficult and disturbing for Wed and her husband as parents (to leave their child without care). In addition, she expressed her dissatisfaction with the fact that the Centre failed to meet her son's need for frequent appointments, yet she had no other choice but to accept the situation.

“Are we happy with this situation? No, we are not for sure. We want him to move.” (Lines 258- 259)

Wed seemed unhappy and upset about the provision of services and the interruption of the child's sessions as she constantly demanded more and for change to happen. However, not having her requests and demands being addressed or considered made her experience the feeling of injustice. She touched on some of the issues she struggled with and things she felt during her child's rehabilitation at the Centre, which were very important to her. These were around the feeling of not being heard, the injustice and the frustration at losing her child's right to have proper treatment that meets his needs and her expectations. She sounded irritated and shattered when saying the following:

“We have experienced injustice; you feel the injustice!” (Lines 318- 319)

Wed was feeling annoyed and confused about not seeing any real improvements in the equipment used to treat children at the Centre. The equipment was old and “ruined”, according to, which seemed to be one of the major issues that she encountered.

*“Look at the bicycles here; they are destroyed. The walkers are not working.”
(Line 268- 269)*

She felt helpless and like a 'beggar' for her child's rights due to her desire for additional equipment. Furthermore, she found it frustrating and disturbing to see donations used for personal gain, as she regarded it as losing her child's rights.

*“It is like we are begging them “give us, give us equipment, get for us devices”.
There is no use... the support they are saying for the children... where is it?”
(Lines 281- 284)*

Equipment was not the only thing that Wed was dissatisfied about. She was also not pleased with the current situation of not having a waiting room for mothers to sit in, take a break and relax while they are with the affected child at the Centre.

“Even the mothers! Put them in a waiting room. Maybe the mother wants to have some space, wants to breath. She is sitting in the corridor.” (Lines 290-293)

She strongly condemned this situation and found it upsetting as she felt that there was no privacy from all the people coming in and out of the Centre, which was sensed as disrespectful to her.

“Mothers leave their houses at 5 am and come at 7:00 am. Okay the mother has her own privacy and wants some space, wants to eat. In the corridor? Everyone coming and going can see her? And the drivers bringing children in! Where are we?” (Lines 293- 297)

Wed wished to have her sacrifices of leaving other responsibilities to be present with the affected child acknowledged and respected. All she desired was to be respected and to be given her simplest right to have a private waiting room for mothers to rest and switch off.

“I mean, feel for the mothers who leave their other children just to come to the Centre with their affected child. Feel for them a little bit. Give them a room since you are leasing the empty spaces to other schools and taking their money!”
(Lines 297- 301)

Despite the fact that all that Wed wished for was to be heard and granted her desires, she was disappointed by not seeing any response to her and the other mothers’ demands.

“The mother wants someone to listen to her. We talked a lot, and the mothers met and wrote a list of things and took it to a responsible person, but we did not see anything. They say “okay we will do and do”, but we did not see anything.”
(Lines 346- 349)

Although the provision of assistive devices was a form of financial assistance, Wed felt that this support was somewhat limiting for them because they were required to provide evidence of their family's financial situation and that they were in need of assistance.

“But when you bring them papers, that the father is in debt or you have a rental contract, they help you with the orthosis and with the walker. They give it to you, I mean, the social services... ah... could give you this.” (Lines 54- 59)

While having useful devices like the orthosis was beneficial to her son, they formed a challenge to Wed and created an additional burden. She struggled with convincing her son to wear them in the first place and expressed how complicated this process was even when the child is small and how it would be more difficult for older children. However, wearing the orthosis at an older age was perceived by Wed as inappropriate.

“These orthosis he has to wear until 14 years, I mean, it is difficult to have it until he becomes a big man and he’s still wearing it. We barely could make them wear it while they are small, and they don’t wear it.” (Lines 149- 152)

Wed elaborated on her concerns with assistive devices like the crutches that her son used for his gait training. She felt that he needed her full attention while using the crutches as he faced apparent fear, the fear of falling, that prevented him from walking and progressing.

“The crutches... you need to watch him so he does not fall on his face... so you feel that there is not... the child needs more because he has this fear” (Lines 152- 155)

This issue was concerning to Wed as she felt the need for further support for the child. She viewed the role of encouragement and boosting the child’s confidence as the role of physiotherapists, not hers.

“So they are supposed to encourage him “you must hold the crutches like this” because the child with the crutches refuses to walk. You see they have fear. I mean the walker. Honestly, they need encouragement and something like this.” (Lines 155- 159)

As Wed described, she found that the overall process of rehabilitating the child was stressful, which did not change over time and was beyond her capability. The difficulty of caring for a child with a disability resulted in Wed eventually surrendering to the reality of the services offered and reluctantly accepting them.

“every year we are trying and nothing is changing.. the mother is tired.. and we leave it on Allah..” (Lines 360- 361).

5.3.2 Mona

❖ *Participant background*

Mona is a 25 year old mother of only one daughter, Jumanah, a quadriplegic CP child treated in Mulberry-street Hospital for almost a year at the time of the interview. Mona completed high school and worked as a school teacher for two years. She got married and had her daughter, but then she gave up her job to raise Jumanah.

❖ *Interview room description*

The interview was conducted in the office of the head of the physiotherapy department, which was vacant during the meeting. The room was small and had two doors, one at each room end. The room had a window, which was closed and had an office station with a PC, a treatment bed and two stools to be used by the physiotherapists and patients. We sat facing each other; I was facing the window while the mother was facing the wall. The recorder was placed between the mother and myself on the physiotherapist’s desk.

❖ *Mona's experience*

The experience of having the first child born with a physical disability left Mona with a complete feeling of disbelief and shock as this seemed to be a sudden catastrophic event in her life. The way Mona described this experience as “a disaster” reflected the devastation she went through as a new mother because her dreams and hopes of having a healthy child were not met.

“This is my first daughter. She had a complication during delivery or, more accurately, a delay in the delivery which caused this disease. Of course, this was for me a disaster!” (Lines 6- 9)

Mona's shattering experience with Jumanah's birth made her go through what seemed to be a grieving process, as she was living in a state of denial towards the child's condition and struggled to accept the disability.

“But I'm not accepting my daughter's condition fully... until now!” (Lines 81- 82)

Feelings of depression towards Jumanah's unchanged condition, seeing other healthy children, feelings of loneliness and not having someone to help with care, in addition to having other life obligations, have all made Mona feel tired and depressed. The different feelings she was experiencing were described as very conflicting and overwhelming to her, affecting Mona's acceptance of her daughter's condition.

“I mean, as a mother I’m really psychologically down from her illness. I want her to be better. I see other children... okay, I’m tired... okay, I do not have anyone to help me.” (Lines 85- 87)

In addition, the fact that the child’s disability was the first of its kind in Mona’s family made it very challenging and demanding for her and her family to accept it at first. However, Mona felt that she had managed to overcome some of these challenges.

“Okay, this is the first child in the family with this condition. I was the first who had a C-section in the family. So for the family it was... hard. But thanks to Allah, we overcame these things.” (Lines 88- 91)

During Mona's struggles to accept Jumanah's condition, she felt lost and in a state of complete shock. She seemed emotionally burdened by the child's disability, as she had lost hope of having a normal child, which was something that Mona had never anticipated.

With all of this, Mona seemed to suppress her negative feelings to fulfil the role of care towards her child. She appeared to follow an ideology of intensive mothering in which she was self-consciously committed and devoted to her child’s care to the point where she considered Jumanah’s recovery her priority in life.

*“So the first thing... my goal was to treat this girl and see that she stands.”
(Lines 11- 12)*

Although Mona viewed the child with a disability to be a child with special needs needing special attention, the caring process was lengthy and required time and effort from mothers. In addition, having other household work and responsibilities, like cooking, looking after other children and

taking care of their spouse, appeared to be overwhelming and emotionally draining on her energy as a mother.

“Especially when the child is a child with special needs, he/she needs special care, needs an hour to eat, during the day he/she eats so little. And every two hours he/she eats a bit. So this requires effort from you as a mother, and you have other children and a husband and have to cook.” (Lines 207- 211)

This increased burden has affected her role and involvement in the child’s rehabilitation and care; nonetheless, Mona acknowledged her role and considered it to be of essential value. However, from her low tone and hesitation, this role seemed to be considered insignificant and limited only to doing exercises at home for her child and nothing else.

“Only in the exercises... I do not feel there is something else. It is just in doing the exercise and so on.” (Lines 77- 78)

She sensed that she was obliged to take care of her daughter’s health as this was her inevitable role as a mother and felt that her wishes and needs were not of great value, but rather the exercises were.

“What is really important is that you do the exercises for the child, no matter what your needs are... and after all she’s your daughter.” (Lines 44- 46)

Mona felt that her opinion was not considered, which impacted her involvement in Jumanah’s rehabilitation. From her irritated tone, she disliked these behaviours from the therapists. Mona

felt that in order to have good communication and involvement, the therapist should be flexible enough to allow such a process of exchanging questions to take place; however, this was not always the case.

“Not all the therapists are asking for that and this. I mean, we see not only one physiotherapist; we see a lot. So not everyone is flexible with you... no.” (Lines 65- 67)

Mona's lack of involvement in her child's treatment was also impacted by her image of the physiotherapists as professionals and her lack of self-confidence. According to Mona, physiotherapists are the experts in her child's care, rather than herself, because she was told so by them.

“They tell me “We know better, we know the best for your child”. The physiotherapists here know my daughter and are more knowledgeable.” (Lines 53- 55)

Mona's self-confidence was suppressed by what some of the therapists, who said to her about them knowing the best for her daughter and by their objections to her suggestions and desired treatment. Even when she tried to get involved in interactions, like asking for further exercises, the physiotherapist made Mona feel that she was pushing them to do what she thought was the best for her daughter and that her desires were not appropriate and suitable for the child's current condition.

“Okay, I ask for things and she tells me “no you are rushing”. I, as a mother, I want my daughter to improve more, I want a variety of exercises, but the

therapist tells me “You are rushing, wait, there are better exercises.” (Lines 55-58)

Mona went on to describe feelings of astonishment and shock towards the therapist's reaction to her wishes for guidance and direction on where she could take her daughter for more intensive sessions. To her, her daughter's improvement seemed to be a personal achievement and an important matter; however, she felt it was not considered.

“Last time when I was in the physiotherapy session, I was surprised by the therapist. She told me “You are exhausting your daughter... do not take her to any other places, this is enough”. But I want to intensify the treatment for my daughter so that she will improve more, for me and for my daughter. She told me “no you do the exercises at home”.” (Lines 113- 119)

Mona felt that the physiotherapists opposed her desire to support her child's improvement; which has left her in a state of confusion, as no sensible explanation was provided. Though she was advised to stick to the given exercises to do at home, Mona faced some challenges and struggled when doing such a task. This might be attributed to Mona's demanding role at home, having life obligations, and not having someone to help, as mentioned earlier in her narrative.

“Okay, but sometimes to be honest I cannot do her the exercises at home.”
(Lines 119- 120)

Mona's lack of confidence and what the therapist has said to her have implanted the idea that they were better and more knowledgeable than her. This has made Mona accept the therapist's objection to her wishes and desires, consequently limiting her involvement.

*“And I accept this from her because she is educated and knows better than me.”
(Lines 59- 60)*

Mona’s lack of self-trust, and the feelings of not being considered or empowered by the physiotherapists, made her avoid involvement in the child’s rehabilitation. From her point of view, in order for her to participate in the child’s rehabilitation, physiotherapists need to be flexible to allow for communication, information exchange, and guidance. Mona reflected on one of her positive experiences with a physiotherapist who was flexible with her and keen to ask for her opinion. This made her feel respected and happy about it.

“I came across a therapist who would ask me “what do you think about this exercise? Do it for her to strengthen her. And this exercise is really useful because of this”.” (Lines 67- 70)

Mona felt some reassurance from this physiotherapist’s positive attitude towards her. For her, being asked questions and considered in the process of decision-making were viewed as essential and a source of comfort. She sensed that it was her right as a mother to freely inquire about her daughter’s rehabilitation and be fully informed.

“I was really relieved that day. Okay, you take my opinion and I understand why this exercise is given. I can ask ... this is my right to ask because this is my daughter. I need to ask to see what a certain exercise does, it’s benefits.” (Lines 70- 74)

Such involvement made her feel respected and relieved about the child’s rehabilitation and helped with better understanding of the exercises given to her daughter, which seemed to be of

great value to Mona personally. Indeed, it was thus building her self-confidence and helping her in facilitating and improving the child's condition.

“...which helps me in doing it... to improve my daughter's condition of course.”
(Lines 74- 75)

Mona highlighted the importance of communication and information sharing between her and the physiotherapist as she viewed it as a source of relief and comfort and a way of understanding each other. Understanding the rationale behind a suggested treatment or the objection to the mother's desired treatment and being actively involved were highly important to Mona.

“It is important in understanding what she means, what the therapist wants, what is her new treatment plan, and based on what is she doing this exercise.”
(Lines 129- 131).

However, she felt the information provided was limited to the child's condition and progress. When Mona attended her follow-up appointment, she felt that the therapists asked for a brief update on Jumanah's condition but did not involve her further as she desired. Mona viewed the communication and exchange of information as a one-way rather than a two-way process, as she perceived herself as a source of information regarding the child's disability. At the same time, the physiotherapists evaluated the child's condition, but they did not provide her with any feedback.

“She just comes and ask you about your child in the beginning, and after a while she would ask about the improvement, what are you focusing on, and if the tension in her hand has decreased or not. She takes from you the information and at the same time she sees your child's condition, that's it.” (Lines 143- 148)

Mona considered guidance from professionals to be highly beneficial, particularly in removing the confusion of not knowing what was best for her child and the fear of affecting her child's disability negatively.

“But will it work? Until now I want to ask the doctor, but I could not find the right doctor to answer me. Okay, maybe this medication will benefit my child, but I’m afraid that it might worsen her case.” (Lines 191- 195)

Not being able to find the right person to answer her queries when needed had made her write down a list of questions on the off chance that she managed to see the doctor. However, even if she did see a doctor, Mona felt she might not find answers to all of her concerns.

“I go to the doctor, and I have a full list of questions to ask.” (Line 195)

Mona seemed deeply distressed by the situation, so I was interested to know whether she sought help, support or direction from physiotherapists. Unfortunately, she avoided seeking help as she felt that therapists did not have enough time to listen to her concerns because of their high work demands. Time limitations were seen as a barrier to not seeking help or guidance.

“Maybe because of the time limitations, they are busy” (Line 162).

Mona criticised herself and the physiotherapists for this, as therapists were struggling with time limitations and high working demands while she was more focused on her daughter’s treatment and nothing else. The overwhelming exercises required Mona’s full attention and focus was being directed towards care rather than asking for support or direction.

“I do not blame them only for that, but sometimes there are a lot of patients and sometimes I’m focused with my daughter. I focus on my daughter’s exercises because sometimes each therapist does a different exercise, so I memorise every exercise with each therapist.” (Lines 164- 169)

In addition to being overlooked by doctors, not knowing what was best for her child and the lack of guidance were regarded as sources of distress and depression for Mona.

“At the same time, the doctors themselves depress me. I mean, until now I do not know the right centre for my child’s condition! Still. I ask, but there is no response. (Lines 107- 110)

In Mona's opinion, communication between her and the physiotherapists facilitated her participation in rehabilitation, and made her feel respected, and reassured her. The exchange of information was thought to promote guidance and understanding of why the treatment was being conducted. Nonetheless, the information seemed insufficient as Mona sought it from different resources but could not find the right person to address her concerns.

Being cared for was perceived by Mona as a form of collaboration and a source of relief. The partnership between Mona and the physiotherapist was regarded as very important; however, to her, the collaboration came in a different form. Mona perceived the therapist showing care and consideration towards her and Jumanah as a form of cooperation.

“Collaboration is for sure quite important, especially when the therapist is caring, when she comes and asks you “what happened with you, do you feel that she rolled today?”” (Lines 218- 220)

The feeling of being cared for and respected gave Mona the push and encouragement to proceed with the child's treatment, which was positively reflected in her care of Jumanah. This positive feeling seemed enough to make Mona leave whatever responsibilities she had and devote herself to her daughter's care and exercise.

“Even if I'm busy, I say to myself “tomorrow the therapist will ask me what I did”, so I go to my daughter and do her exercises. I leave everything in my hands and do the exercises because there is someone who is asking and caring.” (Lines 223- 227)

Having someone to share the burden of care with and having regular follow-ups by the physiotherapist was of great value to Mona personally and seemed to have a positive effect on Mona's care as it gave her the boost she needed to fulfil her care role.

“Okay, when I have someone to follow-up with me on a daily basis, this follow-up is important to me, so I would be encouraged and work better when I have someone with me helping me.” (Lines 120- 123)

Throughout the interview, Mona sounded devastated and unhappy by her situation as she struggled to achieve her hopes and wishes of having her child improve and be well prepared for life.

*“I wish for anything that will benefit my child and will prepare her for life.”
(Lines 200- 201)*

In addition to this, and regardless of how overwhelming the variety of Jumanah's exercises and rehabilitation were, Mona viewed the physiotherapists as her "only" hope for the child's condition and improvement.

"They are my only hope, and I stopped everything for my daughter, and I'm hoping that my daughter will get better." (Lines 169- 171)

Mona considered additional services, such as occupational therapy and speech therapy, as very useful and of great help to her daughter in preparing her for daily life activities and improving her condition.

"I wish if they can provide occupational therapy, speech therapy... things that qualifies them in life." (Lines 180- 181)

5.3.3 Basmah

❖ *Participant background*

Basmah is a 27 years old mother of only one child, Adam. Basmah completed her bachelor's degree in Arabic Language Studies and worked as a teacher. She left her job to focus on Adam's rehabilitation. At the time of the interview, Adam was 18 months old. Adam had a Hypotonic CP, causing developmental delay, and had been receiving treatment at the Centre for intermittent intervals since birth.

❖ *Interview room description*

The interview took place in the head of the physiotherapy department's office, which was vacant at the time of the interview. The room was small and did not have a window. There was a book cabinet, a desk with a PC and a chair and two armchairs facing a couch. I sat on one of the armchairs, and Basmah sat on the other, next to me, both facing the walls. The office door was locked with a key so no one could come in (the mother agreed to this for privacy), and staff were informed about the interview taking place. The interview was done after the child had his session, as arranged with the mother, and he was in his baby stroller during the interview. Basmah was informed about the study by one of the physiotherapists and had the chance to read the interview guide and study information before the interview. On the interview day, I introduced myself to Basmah and explained my research aim and objectives. Basmah was given a second chance to read the interview guide; however, she decided to proceed with the interview straight away. Basmah was informed about her right to withdraw from the study at any time without any obligations; she was assured that her information would be confidential and that withdrawal, if she so chose, would not affect her child's treatment in any way. Basmah seemed very enthusiastic about sharing her experience.

❖ *Basmah's experience*

To Basmah, caring for her son with a disability was an overwhelming task as the responsibility and task of the child's care were left to her only. Feelings of loneliness and sadness were reflected in Basmah's tone, indicating how she struggled to bear this load all by herself.

"The big burden is on my shoulders only!" (Line 238)

She felt that the motherhood duties necessary for the child's care and the high expectations from her as a mother were what made her feel obligated to care for Adam. Basmah believed that it was her inevitable role as a mother to be responsible for the child and be the primary carer.

*“I as a mother, I’m the one who is supposed to always keep an eye on my son!”
(Lines 239- 240)*

This has led Basmah to adopt the most prominent role in the child’s care, during his sessions at the Centre and at home. She viewed her role at home as doing the exercises and precisely following what the therapist told her. Basmah went on to describe how her commitment to the exact treatment was because of her lack of self-confidence and fear of adversely affecting the child.

“I could say 90%... ah... without the information. I mean, with the information they give us and the practice at home exactly without the fear of having a reflex effect, so I don’t do more, I have a role.” (Lines 197- 200)

Furthermore, Basmah's involvement in decisions regarding the child's rehabilitation was limited, as she indicated how she relied on the physiotherapists to make such decisions. She avoided such participation due to her lack of clinical background and knowledge, believing that knowledgeable physiotherapists were the experts and were more experienced than her.

“No, honestly I did not participate because I don’t have a clinical background, and I respect medicine and the profession, so I did not participate.” (Lines 176- 178)

It seemed that Basmah’s lack of participation was something personal. Despite not being given the opportunity, she stated that she would not participate in what she called ‘*medical opinions*’ but instead would express her personal viewpoint. It was her self-preference not to participate, as she lacked the confidence and considered participation in decisions to be an “*interference*” that she resented.

“No, no, no... I never had the chance, and even if I did, I will only give my personal opinion and not medical opinion. I would never interfere!” (Lines 181-183)

She went on to describe the things that she considered to be personal opinions, such as Adam's continued participation in a particular exercise or any modifications or alterations to that exercise. While this may seem like a clinical opinion, it was not perceived that way by Basmah. Since she was the one accompanying her son and closely observing his condition at home, she felt she had the right to make a decision for her son in such situations.

“Like if he needs treatment, needs a belt... ah... if he can continue on this move for one week or two weeks? Or if he needs to move to another exercise? If I saw that the previous exercise did not give any results so I could decide for him to continue with it or not. These are the personal things. I mean, I see him at home.” (Lines 186- 191)

The primary role that Basmah was adopting could also be attributed to the family's and father's lack of involvement in the child's care and rehabilitation. She sounded sad as she described how both her family and husband were not involved in Adam's care, and their role was almost non-existent. Consequently, Basmah felt responsible for asking about the child's exercises and how they were done, even when she did not feel like doing them.

“Yes, from both sides to be honest. I mean, if I did not do the exercises and so on, I tell myself “Basmah you can read more, you could ask the doctor”. Everything is on me.” (Lines 243- 246)

Though Basmah denied the role of her husband and family members in Adam's care, she pointed out the role that the father played in rehabilitation, which was transportation. The father's limited role in participation in care and doing exercises made Basmah feel alone as she did not have someone to share the care with.

"I cannot deny the role of the father in the transportation and so on, but in the exercises, no." (Lines 248- 249)

Basmah felt that she was left out without any help from the father and went on to explain how his limited involvement was attributed to his lack of knowledge concerning the mechanism of exercises because he was not present with her during the sessions. Basmah sensed that despite her continuous efforts to teach the father how an exercise was done, he still could not actively get involved in Adam's rehabilitation, as he lacked confidence and was hesitant.

"...because he did not sit with me and the physiotherapist. He did not see the exact exercise. So no matter how many times I teach him, he is always a bit hesitant." (Lines 251- 253)

The father's absence in sessions was not an individual choice but rather an imposed situation that Basmah and her husband had to accept. Though she personally requested and expressed her wish to have the father in, he was banned from entering the sessions with Adam. The way she described the situation as "*forbidden*" reflects how she felt confused about the therapist's opposition to her desire to have the father with her and struggled many times with such a request.

“They would not allow him in; it is forbidden. I have asked them many times in this Centre and in the other Centres, but they said no!” (Lines 256- 258)

The managerial rules of the hospital are to have a ladies-only department, to ban fathers from entering the sessions with their children. To Basmah, this segregation was seen as something unnecessary in clinical settings, and she denounced this ladies-only policy as she felt that the father was forced to be isolated and excluded from the child’s care.

“There is no need for the 100% isolation.” (Line 266)

In Basmah's experience, her involvement in the child's rehabilitation was somewhat intermittent because she did not attend physiotherapy sessions on a regular basis. She felt compelled to sacrifice her own life choices and leave her job for the sake of her son as her other obligations, such as her employment, interfered with the child's treatment. As for Basmah, employment posed an obstacle to Adam's care and rehabilitation, resulting in irregular appointments.

“But I was not regular because I had to work, so I quit my job, and I was then regularly coming until he was able to sit.” (Lines 36- 38)

In addition, Basmah identified additional obstacles to rehabilitation, such as the inaccessibility of physiotherapy centres. Basmah has found it challenging to adhere to her treatment plan due to the amount of time and effort it requires due to her inability to access the right treatment Centre and transportation issues.

“Then I stopped coming because the centre was far from my house. I mean, all the centres are not close to me; it takes an hour to go and an hour to come back, and so on” (Lines 38- 40)

Limited transportation and the inaccessibility of centres seemed to be a crucial cause for the child’s irregular sessions and interruption of rehabilitation, which was a prominent issue raised in Basmah’s narrative.

“I continued the physiotherapy for 4 months until he was able to sit. He sat, and then I stopped bringing him because of the transportation” (Lines 52- 54)

Her lack of awareness regarding the child's progress and regression has also affected the child's attendance at rehabilitation sessions. Basmah believed that the child's development was a spontaneous process that occurred without the assistance of physiotherapy. Since the treatment was consuming a great deal of her son's time and interfering with his other medical appointments, she decided to discontinue it temporarily.

“So like I told you, I quit the physiotherapy because I wanted him to move by himself, and he had an eye appointment, so I wanted to save some time.” (Lines 160- 163)

In the narrative, Basmah expressed distress and sadness over the child's delayed referral to physiotherapy, which was a major concern for her. As it appeared, Basmah was very irritated and upset to see such an attitude from a physician who was supposed to be knowledgeable and alert.

“No, she did not direct! I personally requested that! So I do not know if she thinks that the physiotherapy has no importance.” (Lines 386- 388)

To Basmah, the early referral could have helped her with her struggle with her child’s disability and would have facilitated her ability to adapt to such difficulties.

“If she directed me to a doctor or physiotherapy from the age of 6 months, I would’ve overcome this.” (Lines 383- 385)

The lack of knowledge and experience Basmah had in dealing with such cases, along with her lack of awareness of the benefits of physiotherapy, led her not to seek guidance. She was psychologically living in a state of confusion and sadness about the child's disability, which prevented her from knowing the right thing to do at that stage.

“I did not know that the physiotherapy has benefits at that stage. I knew that he couldn’t raise his head, and I was really sad, really sad.” (Lines 404- 406)

Basmah showed initiative as she sought for an explanation about the child’s condition online. Seeing the practice of other international doctors outside of the Kingdom has given Basmah the courage to ask for a child’s referral.

“I explored the internet, and I saw people and how children are. In Egypt the medicine is advanced, the physiotherapy. So I benefited from those Arabic doctors who talk a lot about such cases. So I asked for referral.” (Lines 417- 420)

As she observed the progress of her son's rehabilitation, she appreciated the role that physiotherapy played in his improvement. Consequently, she felt relieved and happy about the care and treatment received.

*“He raised his head, and I was happy that the physiotherapy had an effect.”
(Lines 159- 160)*

As for communication, Basmah appeared to have limited communication, which was her personal preference, as she preferred to focus on child exercises rather than communication. She felt that the time allocated to the child's treatment was very precious but very limited and would not allow this communication to take place. Additionally, Basmah's lack of self-confidence in her ability to understand what she was being told was also viewed as a reason for avoiding communication. In her opinion, spending time on a conversation that might be understandable to her or not was a waste of time, limiting her participation in communication.

“I just focus on the exercise more than talking. I do not waste a single minute with them... ah... I just look at them and focus with them because it is only half an hour, the exercise is only half an hour, so I do not want to waste it on a dialogue that I may or may not understand, you know?” (Lines 271- 276)

Although the dialogue between parents and therapists was lacking, Basmah considered it to be a form of support that she valued.

“This thing I missed in all the centres to be honest; the dialogue between the doctor and the patient.” (Lines 213- 214)

Basmah felt herself uninformed as a mother who lacked confidence and sufficient information about her child's disability and felt lost not knowing the best for her son. A dialogue such as this was therefore viewed as a means of helping her personally and all new mothers in overcoming their fears.

“So I wish if they... especially if the child was the first for the mother, she lacks a lot of information... it's maybe a normal thing but with the dialogue they will be able to overcome a lot of concerns.” (Lines 214- 218)

Additionally, Basmah described how she was confused and struggled with not knowing how things were done as she did not have a clear plan to follow. Therefore, she appreciated having a treatment plan in advance as it seemed to save her time and make her life and other obligations easier.

“A full plan so that the families know what is happening with them.. so that they can organise their schedules based on it. This would be great! And it would save time, especially as services are not available at every district.” (Lines 143- 147)

Basmah viewed communication and collaboration between therapists as highly important and beneficial because this saved time. She expanded on this by describing how, to her, collaboration was viewed as the physiotherapist having the power to refer and having more cooperative communication between physicians and therapists. However, she felt that in her experience, collaboration was completely absent as she described it as “zero” rather than indicating it as ineffective only.

“Zero! Zero! And this is not the fault of the physiotherapists. No, it is a defect in the administration system of the hospital!” (Lines 329- 331)

She went on to describe how this impacted her when she sought devices for her son. The referral process was very exhausting, which took a lot of her time and energy as a mother and was something beyond her imagination. The way she described her experience indicated how she was burdened and overwhelmed by the situation but could not do anything about it.

“You cannot imagine how I spent a year... if I could count the times... just roaming around in the clinics personally. I just go back and forth, from a doctor to the other and from a referral to the other.” (Lines 334- 338)

The long waiting time for the referral to get a certain device was perceived by Basmah as a very tiring and lengthy process, as it wasted her time personally and her son’s time. According to her, being unable to afford and get devices from other places was very exhausting, especially for families who are not financially stable.

“I mean, this takes time and wastes the patient’s time. This thing is important and could be exhausting, especially if you only have one source of income for example.” (Lines 347- 349)

Basmah believed that empowering physiotherapists and giving them the right to refer patients directly would be of great value as it would incorporate their views with the physician's views, thus promoting better physiotherapy services.

“But she does not have the power to refer my child to another doctor. She said “I cannot, I cannot”. Whenever I ask any therapist, they all say “we cannot refer you”. I feel this will integrate her views with the views of the orthopedic doctor, which will facilitate the physiotherapy.” (Lines 124- 129)

Having the power to refer was not only viewed as having a great impact on the mother, according to Basmah, but also to have a significant influence on the therapists themselves and their clinical practice. Having enough resources and the power to refer was viewed as a facilitator to care, whereas their absence was considered a barrier to service provision, as perceived by Basmah.

“The doctor will try his best if he has enough resources and power. He will do his best. I mean, he will not come to work, and he does not know his job, but if he comes and he does not have enough power, what is the use? And without enough resources what will he do?” (Lines 367- 371)

Basmah raised several concerns about the type of care she desired. One example is the incorporation of various therapies, which appeared to save time and aid in the child's adaptation process. Not only did this have an impact on the child, but Basmah believed it also provided relief to her, the family, and the physiotherapist.

“Yes, he will improve a lot. And you combine the physiotherapy with the speech therapy and the behavior and developmental skills, so the child will not have that resistance, and even the doctors will be relieved, the therapists and the parents, and will take enough time.” (Lines105-109)

Time seemed a very important matter to Basmah as she emphasised its importance in rehabilitation many times in her narrative. More specifically, giving the child enough treatment time to overcome his fears and adapt to the setting and rehabilitation. Additionally, the length of appointment was seen as an essential aspect of care, according to Basmah, which needed consideration.

“Second thing, the time! The time is very very important in the physiotherapy, especially when the child resists and the muscle resists, so what do you think about the appointments? Ah... the time is really important. The length of appointments.” (Lines 360- 364)

Improved communication between Basmah and the entire team treating her son, as well as a more efficient referral process, were deemed to be among the areas for improvement. In addition, she found the process of pursuing devices and assistance for her child to be exhausting and stressful, and she wished for improvements.

“I have a lot of wishes and dreams for my child Adam to walk. But the mothers roam around for years and years from one doctor to the other. This is exhausting. So there must be a good communication between us, the doctors and the entire team... the entire medical team.” (Lines 374-379)

Basmah ended the interview by wishing for better rehabilitation services and for change to happen. Her enthusiasm to participate in the study reflected her desire to have her voice heard for change to happen, not only for her child’s benefit but also for the sake of other children.

“I wish for change to happen. When I read about your study, I was so excited to participate and share my experience with you in hope that services will change... for my child’s benefit and other children also.” (Lines 422- 425)

5.3.4 Salma

❖ Participant background

Salma was a 37 years old mother of seven children, including her daughter Hala. Hala was Salma’s fifth child, who was born without any physical impairments but then had medical complications after the age of 2, resulting in quadriplegic CP. Hala had been treated in Roover Hospital for only a few months when the interview was conducted.

❖ Interview room description

The interview was conducted in the early morning after Hala’s physiotherapy session was over, as this was the mother’s request. The interview took place in a treatment room, which was vacant at the time of the interview. The treatment room size was good; it did not have any windows but had cartoon drawings on all four walls. There was a treatment mat, a spider cage (treatment tool), stairs used in gait training, a small TV, and a working desk with two stools for the use of physiotherapists or parents. We sat facing each other, facing walls, and the recorder was placed in the middle on a stool.

❖ *Salma's experience*

Salma struggled with her child's medical condition was challenging as she found it difficult to comprehend. She was shocked and confused when Hala was first admitted to the hospital and went into a coma at the age of 2. The unexpected deterioration in Hala's condition has left Salma terrified and in full disbelief, as she did not have a confirmed medical diagnosis and did not know what was happening with her daughter.

"I was very scared about ah...." (Line 21)

The experience could not have been worse for her, as the physicians who initially treated her daughter's condition showed some negative attitudes. The doctors told her to give up on her daughter's disease, as they seemed to consider it a dead case. This was depressing and devastating for Salma and was reflected in her sad, low tone.

"In the hospital they told me "leave it to Allah". They meant she would not survive because she was in a coma and they did not know what was wrong with her, so they said "it's over, the girl is over"." (Lines 22- 26)

Regardless of the frustrating and suppressing talk that Salma heard about her child's condition, she seemed to be a believer who had a strong religious bond and faith, as she believed that Allah's will would enable her daughter to get better.

"I had strong faith and hope in Allah's will, and I was confident that Allah would let my daughter live!" (Lines 29- 31)

Salma showed commitment to childcare even when her daughter was admitted to the hospital as she accompanied the child throughout the day, praying for her to get better. This reflected Salma's perseverance, strong hope and faith in her daughter's improvement.

“Every day I read to her versus from the holy Qur’an. Every morning, and I did not leave her until it is evening.” (Lines 31- 33)

In spite of the child's improved condition, she had complications that required physiotherapy . Salma seemed 'lost' as she tried to find a rehabilitation facility that could treat the condition of her child. Despite the exhausting experience of roaming between centres, Salma's commitment to finding the best care for her child was evident in her narrative.

“I was like, you know, lost, looking here and there, but I could not find the perfect physiotherapist who would treat my child perfectly.” (Lines 139- 141)

Finding the right Centre, at last, seemed to impact Salma's mindset as she felt relieved to find the place she believed was the right one and made her happy and satisfied.

“Now I'm settled in this centre, and honestly I like it here so far.” (Lines 144- 145)

The way the physiotherapists approached Salma and her daughter and how they provided the services to them by being courteous made Salma feel satisfied with the services she was offered.

“Honestly, they are... ah... they provide services with an open heart, and they give us exercises faithfully, honestly speaking.” (Lines 38- 39)

In addition to this, being involved and considered in the child’s rehabilitation, along with feeling respected and comfortable, has made Salma’s experience at this Centre a positive one. Salma expressed how she was involved in all aspects of childcare, including decision-making, which made her feel relieved and happy about it.

*“They are making me very comfortable, and I share everything with them”
(Lines 98- 99)*

“They always ask for my opinion, and they involve me.” (Lines 101- 102)

The physiotherapist's positive attitude and encouragement for Salma to actively participate in the child's rehabilitation had empowered her to take the initiative and engage in her daughter's physiotherapy and rehabilitation.

“During the session, I sit with them, and I observe how they give her the treatment so that I can do it at home.” (Lines 95 -96)

As a result of this encouragement and empowerment, Salma believed she played a key role in her daughter's rehabilitation as a mother. She showed devotion and commitment to the child’s physiotherapy and dedicated all her efforts to the child's care, as she seemed to be her hope in life.

“I take care of her in everything... ah... She is to me everything you know! I dedicated myself for this girl. I do her physiotherapy, I feed her... I mean, I take care of her generally, so for sure I have an important role.” (Lines 87- 90)

Salma believed that the primary function of physiotherapists is to assist, as she described them as *“only helpers”* who provided her with guidance and support regarding her child's condition. However, she considered that most of the responsibility for the child's care fell on her shoulders because, as a mother, she played an essential role in the child's care.

“I mean here they are only helpers, and they give me information on what to do at home, and I do physiotherapy for her at home.” (Lines 85- 87)

She appeared to be fully involved in the child's rehabilitation and considered herself as the primary carer who took the full obligation of care though she was offered help from her husband and the child's siblings. Her refusal of the support proposed by family members seemed to be her personal preference, as she intentionally did not allow it to happen.

“Her father is helping me, but I do not allow him.” (Lines 188- 189)

The father's and siblings' initiative to help the mother with the responsibility of the child and to get involved in the child's rehabilitation was opposed by Salma due to her fear of them adversely hurting the child instead of helping her improve. Salma's lack of trust in the abilities and knowledge of family members made her adopt the full role of care as she felt more knowledgeable about how exercises were done.

“No, no he wants to help and they want to help! But I get scared, you know, because she has a dislocation in the lower limbs, and I’m afraid that she will have one in her upper limbs.” (Lines 191- 194)

Salma’s fear of negatively affecting the child’s medical condition was considered a barrier to family involvement and as a consequence, has led her to assume the role of the physiotherapist.

“But you know, I’m adopting the physiotherapist’s role.” (Lines 199-200)

Additionally, Salma relied on the internet and observation of the different physiotherapy practices to build and gain more knowledge and experience around her daughter’s rehabilitation. Her initiative to learn from the other techniques that she saw with Hala’s treatment in various centres reflected her devotion and commitment to the child’s physiotherapy and improvement.

“I work on YouTube. I watch videos on YouTube. Even when I went to India, I observed their work and even in the different hospitals that I went to.” (Lines 200- 203)

Overall, Salma seemed happy and satisfied with the impact that physiotherapy had on her daughter and by the physiotherapist's work and positive attitude towards her as she viewed them to be brilliant.

“Honestly the physiotherapists here are very excellent.” (Lines 47- 48)

She pointed out some aspects of care that she valued and were essential to her. Salma seemed to appreciate the importance of physiotherapy exercises and the role they played in improving her child's physical condition and abilities.

“They do her massage and physiotherapy, and it is important so that she can raise her head and fixate it.” (Lines 55- 57)

Although Salma appeared to be satisfied with the services and happy about how the physiotherapist would involve her, she highlighted the importance of having a respectful partnership with the physiotherapist. Having a welcoming and optimistic therapist who would provide care with willingness seemed like a valuable point to Salma, which made her feel relieved and happy.

“The most important thing is that they do the physiotherapy while they are smiling and being optimistic; this thing is so important to me. I mean, it's not like one would talk from the tip of her nose. I mean, no she would talk like we are sisters.” (Lines 59- 63)

In addition, Salma believed that the environment of rehabilitation, such as a cheerful and welcoming atmosphere, was the most critical factor in facilitating the child's adaptation and responsiveness to treatment.

“The most important thing is the atmosphere. The atmosphere must be suitable and friendly for the child, and then everything is like a game.” (Lines 160- 162)

Another issue that Salma emphasised was the children's struggle with the fear of the white lab coats the physiotherapists wore, and she went on to describe Hala's own experience and fear of it. According to Salma, this fear seemed to be reflected in the child's psychology and might impact upon their adaptation to the clinical setting. Thus, she wished for friendlier and more colourful uniforms to help children overcome this fear and aid in advancing their rehabilitation.

"I wish, I wish if these white lab coats... I wish because you know the child gets scared from it." (Lines 165- 166)

"So I wish if they can replace the white lab coat with something more cheerful for the children." (Lines 174- 175)

CHAPTER 6 - LOOKING FOR PATTERNS ACROSS CASES: SIMILARITIES AND DIFFERENCES

6.1 Introduction

This chapter highlights the major themes that emerged from all or most of the participants' experiences to provide insight into what was shared and what was different across the physiotherapists' and mothers' experiences and reflections on rehabilitation and family-centred care. The chapter is divided into three sections, the mothers' experiences, the physiotherapists' experiences, and the shared experiences within the four different centres in which the study took place. These data were examined in this way to enable a cross-case comparison of the groups.

6.2 The Mothers' Experiences

This section provides an account of the mothers' experiences of FCC for children with physical disabilities in Saudi Arabia. It illustrates the differences, commonalities and patterns of the participants' narratives to highlight their shared and unique experiences of family-centred care as well as some of their unique ones.

6.2.1 Shared Themes: Similarities and Differences between Participants Superordinate Themes

The shared themes are evident within each of the mothers' interviews and are presented in the table below (Table 7). Table (7) shows the superordinate themes and their subordinate themes from each idiographic descriptive analysis to illustrate shared themes patterns. Themes revealed

by each participant are indicated by using (X), and common themes across all four participants are highlighted in grey.

<i>Mother Shared Experiences</i>				
Superordinate themes	<i>Wed</i>	<i>Mona</i>	<i>Basmah</i>	<i>Salma</i>
Subordinate themes				
Perception of family-centred care	X	X	X	X
Mother's well-being				
<i>Impact of child's improvement on mother's psychological well-being</i>	X		X	
<i>Lack of knowledge and awareness as a source of mother distress</i>		X		
<i>Impact of involvement and consideration on mother's psychological well-being</i>		X		X
Financial status as a barrier to rehabilitation	X			
Perception of physiotherapy and therapists				
<i>Rehabilitation as a lengthy process</i>		X		X
<i>Therapists as the experts</i>	X	X	X	
<i>Physiotherapy as the "hope"</i>	X	X		
Irregular therapies	X		X	
<i>Interruption of treatment as a source of mother distress</i>	X			
The Burden of care and motherhood	X	X	X	X
<i>Struggle with acceptance of condition</i>		X	X	X
<i>Emotional labour and Invisible labour</i>	X	X	X	
<i>Sacrifices of life choices</i>		X	X	
<i>Barriers to father involvement</i>	X		X	X
<i>Time limitations as barrier to care</i>	X	X		
Communication as important	X	X	X	X
<i>Language as a barrier to communication and collaboration</i>	X	X		
<i>Support and guidance</i>		X	X	

<i>I want more information</i>	X	X	X	X
Integration of therapies as useful		X	X	
Child's fear and adaptation			X	X
Feelings of un-satisfaction towards care	X	X		
Sense of injustice	X			
Lack of power to refer			X	

Table 6 Mothers shared experiences

There were three major superordinate themes shared between mothers, which were ‘perception of family-centred care’, ‘the burden of care and motherhood’, and ‘communication as “important”’.

6.2.1.1 Perception of Family-Centred Care

Since the purpose of this study was to explore the mothers' lived experiences of FCC, their understanding and perception of the concept were deemed to be essential; therefore, it will be discussed first. All four mothers denied knowing the concept but offered diverse understandings of the meaning of family-centred care, as each described it differently when requested. The mothers' definitions and perceptions of family-centred care are presented in the table below (Table 8) using verbatim quotes for each participant that represented their answers to the following questions: “Have you ever heard about the term family-centred care?” and “Could you think what it might mean?”. In line with the IPA approach, it is assumed that these understandings have been developed and derived from the mothers' experience with their child's rehabilitation and care.

Participant	Perception of Family-Centred Care
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Wed	<i>"You mean ahhhh the centre helps the family to get treatment in other centres on the days where they are not being treated in the centre.?" Lines 42-44</i>
Mona	<i>"No (short pause), you mean home care?" Line 37</i>
Basmah	<i>"I think it mean ahhhh if the medicine ahhh is clear to the mother and they engage the mother in the plan, I think this is what the name implies.. the families has a plan to follow at home.. is that right? What does it mean?" Lines 303- 306</i>
Salma	<i>"Maybe the family provides care for the child ahhh I do not get it I mean I do not get it" Lines 70- 71</i>

Table 7 Mothers' perception of family-centred care

After offering them an explanation of the concept (as described in p.20, section 2.6.2) to promote thinking, they all considered FCC as different to what they perceived they were receiving in the centres and hospitals where their children were being treated at. Indeed, they felt that current care focused mainly on the child rather than the family. Their responses to the question *"Do you feel that this differs from the services you are offered here?"* are presented in the table below (Table 9) using verbatim quotes for each participant.

Participant	Responses to the question "Do you feel that this differs from the services you are offered here?"
Wed	<i>"Yes yes, here no.." Line 51</i> <i>"It differs in that the child take sessions and goes outside and there is nothing else.." Lines 53- 54</i>
Mona	<i>"Yes and more accurately here they focus on the child only.." line 45- 46</i>

Basma	<i>"Yes 100%!! Here they only deal with the disabled or the child who has a physical disability only! Who brings him? the mother, the driver, or the nanny.. it does not matter! he just go in and do the exercises and goes out.." Lines 312- 315</i>
Salma	<i>"Until now I feel that services are directed to Hala." Line 81</i>

Table 8 Mothers responses

6.2.1.2 The Burden of care and motherhood

The 'burden of care and motherhood' was one of the significant and vital themes shared by the mothers. It reflected the struggle that Mona, Basma and Salma were going through with accepting their children's disabilities. The mothers had experienced what seemed to be emotional labour, a term created by the American sociologist Arlie Hochschild (2012) to describe the suppression of their feelings to fulfil a job requirement. In this study, the mothers seemed to suppress their emotions and compromise their lifestyles to complete the extra duties of care needed to support their child along with the general caring responsibilities and household tasks required of them as mothers, which is known as invisible labour. Wed, Mona and Basma experienced feelings of loneliness as they thought they had no support at home from their respective partners and the fathers of their children but instead carried the entire burden of care on their shoulders as mothers. Barriers to the father's involvement were reflected in the four narratives. Despite how diverse these barriers were, all impacted the fathers' participation in the child's rehabilitation. Though all mothers were keen to bear the responsibility for their child's care and rehabilitation, their time limitations seemed to make the child's physiotherapy and exercise a burdensome task that could not be sufficiently fulfilled. This burden of care appeared to have an impact on the mother's perception of motherhood, mothering roles and how much the mother cares for the child with a disability, with some mothers perceiving physiotherapy exercises as an additional burden that interfered with their motherhood duties and care. The burden of care and motherhood will be discussed further in the following chapter (Chapter 7).

6.2.2.3 Communication as “Important.”

The third theme was ‘communication as “important”’, which was regarded as a vital part of the mother’s experience with family-centred care because communication formed the basis for providing information, support and guidance and promoting collaboration between physiotherapists and parents. However, it appeared that all participants were not completely satisfied with the level of communication that took place and the information that had been provided as they all desired more. This included information and communication about the child’s condition, progress, rehabilitation and future outlook, which were of value to mothers and informed their understanding and awareness of the child’s condition. Additionally, language differences were considered a barrier to this communication and the collaboration between physiotherapists and parents, which Wed, Mona and Basmah experienced and felt unhappy about. Consequently, in turn, this has been perceived as affecting the amount of support and guidance they were offered, which was a frustrating experience for both Mona and Basmah as they struggled to cope.

6.2.2 Mothers’ Unique Experiences of Rehabilitation and The Burden of Care

This section will illustrate the significant differences that emerged from the cross-case analysis regarding the rehabilitation process and the approach to the burden of care offered by Wed, Mona, Basmah and Salma.

Wed was unique in describing her negative experience with the child’s rehabilitation and family-centred care as she perceived herself to have been treated unjustly. The sense of unfairness resulted from Wed’s feelings that her desire for her child to be treated more frequently was not met by the physiotherapists, which made her experience more challenging. Wed seemed to be burdened by the responsibilities at home and faced time limitations that prevented her from taking a prominent role in rehabilitation at home; thus, she preferred further assistance and support from the Centre to help her child improve. Mona’s experience with her child’s disability

and rehabilitation was devastating to her personally as she struggled to accept her child's condition initially and struggled to find guidance and answers to her concerns.

Mona expressed how having someone from the beginning who provided advice, support and information appeared to ease things for her and was considered a valuable aspect of rehabilitation and family-centred care. Basmah, on the other hand, appeared to be bothered by the lack of support at home and the absence of guidance and assistance from healthcare providers regarding her child's condition. However, a prominent issue was raised by Basmah's experience with rehabilitation, which was the referral process. Her son's referral process to different healthcare professions was perceived to be lengthy and exhausting and took more time than anticipated. The lack of collaboration between healthcare providers, which Basmah felt, and the apparent lack of power the therapists had to refer seemed to make the referral process and support harder on parents, making Basmah's experience more upsetting. She described how she felt that having a flexible referral process and additional collaboration between the healthcare providers within a hospital would be helpful and greatly beneficial to the child's medical condition and her own well-being.

In contrast to the other mothers' experience, Salma's experience with her child's rehabilitation was positive, although at first, like Mona, she struggled to accept the child's condition. Nonetheless, she appeared to assume an approach of complete devotion to the role of caring for her daughter. She adopted the primary role in the child's rehabilitation and did not allow other family members to help her with the child's rehabilitation or care even though she was offered help by the family. This created a barrier to the father's involvement. Salma feared and did not appear to trust family members to play any supportive role in her child's care. She indicated that the empowerment and guidance she received from her therapists inspired her to assume full responsibility for her child's care; however, this added to the burden she felt. In addition, Salma believed that the lack of consideration for the child's fear of new surroundings and the white lab coats worn by the staff negatively impacted upon her daughter's rehabilitation and progress.

6.2.3 Conclusion

This section has shed light on the mothers' shared experiences, which revealed three overarching themes drawn from the mothers' narratives that are linked and are part of family-centred care and form their experiences and meanings of rehabilitation and FCC. It also highlighted each mother's unique experience with rehabilitation and the most prominent matters raised from their individual experiences. What was revealed from their narratives is: the burden of care and its impact on motherhood and lifestyles, the barriers to fathers' involvement in rehabilitation and feelings of loneliness and lack of support that mothers felt, the insufficient levels of communication and the effect of this on the provision of information, guidance and collaboration between physiotherapists and parents. All are thought to be directly linked to family-centred care and have played a role in forming these experiences and the mother's understanding, perceptions and meanings of FCC. This will be discussed in detail in the following chapter.

6.3 The Physiotherapists' Experiences

This section provides an account of the physiotherapists' experiences of family-centred care for the rehabilitation of children with physical disabilities in Saudi Arabia. It demonstrates the differences, commonalities and patterns of the participants' narratives to highlight their shared experiences of FCC and their unique experiences.

6.3.1 Shared Themes: Similarities and Differences of Participants Superordinate Themes

After analysing the findings of each physiotherapist's idiographic experience and highlighting the patterns from their individual narratives, the analysis then explored patterns across cases and experiences. The shared themes were evident within each of the physiotherapists' interviews and are presented in the table below (Table 10). Table (10) illustrates the superordinate themes and their subordinate themes from each of the idiographic descriptive analyses to show shared themes patterns. Themes revealed by each participant are indicated by using (X), where shared themes are highlighted in grey.

<i>Physiotherapists Shared Experiences</i>				
Superordinate Themes	<i>Hanaa</i>	<i>Adam</i>	<i>Maya</i>	<i>Rasha</i>
<i>Subordinate Theme</i>				
1. Perception of Family-Centred Care	X	X	X	X
2. Different roles of care				
<i>Impact of culture on family dynamics of care roles</i>	X	X		
<i>Mother as the main carer</i>	X	X	X	X
<i>Vital role of siblings</i>	X	X	X	X

<i>Barriers to fathers' involvement in rehabilitation</i>	X	X	X	X
3. Limited Role of Support	X	X	X	X
<i>Limited authority to refer</i>			X	X
<i>Similar cases as an emotional support</i>		X	X	X
4. Perception of Disability				
<i>Child with disability as part of family/society</i>	X	X		
<i>Negative stigma around disability</i>	X			X
5. Barriers to Rehabilitation				
<i>Working load and time limitations as barrier to rehabilitation</i>	X			
<i>Child's fear and acceptance as a barrier to rehabilitation</i>		X		X
<i>Culture as a barrier to rehabilitation</i>	X	X		
6. Communication as very important	X	X	X	X
7. Collaboration				
<i>Collaboration with medical team as important</i>	X	X		
<i>Collaboration with the social worker</i>	X	X	X	
8. Parents Education and Awareness	X	X	X	X
<i>The impact of parents' awareness on care</i>	X	X		X
<i>Parents acceptance and compliance</i>	X	X	X	X
<i>The relationship between care and child's progress</i>		X	X	X
9. Parents Empowerment	X	X	X	X
<i>Parents as partners</i>		X		X
10. Facilitators to Rehabilitation				
<i>Integration of therapies</i>		X		

Group therapy as a facilitator to therapy		X		X
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Table 9 Physiotherapists shared experiences.

The physiotherapists shared six major superordinate themes. These were: ‘perception of family-centred care’, ‘different roles of care’, ‘limited role of support’, ‘communication as very important’, ‘parents’ education and awareness’ and ‘parents’ empowerment’.

6.3.1.1 Perception of Family-Centred Care

The first theme to be discussed is the physiotherapists’ perception of family-centred care. The physiotherapists’ definitions of family-centred care are presented in the table below (Table 11), using verbatim quotes for each participant.

Participant	Perception of Family-Centred Care
Hanaa	<i>“What I guess is maybe I have maybe this vague idea that family is incorporated in the ... ah... rehabilitation program..” Lines 792- 794</i>
Adam	<i>“The parents gather in ...ah... one place, and there is like group therapy, or a group of families present and the children are present, and this gives motivation and ahhh there is cooperation, collaboration from the families and from the patients and honestly it gives excellent results” Lines 58-62</i>
Maya	<i>“I heard that they call the mother, the father and the siblings and they support them like <u>“you have a child with a disability and he cannot walk”</u>.. like this....ah... they explain to them for example <u>“he walks or he might not walk”</u>.. if he needs support at home they provide it to them...” Lines 178-182</i>

Rasha	<i>"I feel that it is something that happens if they have a baby who has a problem. Maybe this thing is concerning the family. I mean, like they give them education, psychology, sessions... ah... maybe they show them how to deal with the child at home. I feel that it cares about the family around the child more than the patient himself." (Lines 696- 701).</i>
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Table 10 Physiotherapists' perception of family-centred care

The physiotherapists showed different understandings in terms of the meaning of family-centred care as terminology, and each described it differently. Some definitions were based on what they had heard from others and not on their own perceptions, like in Maya's definition, while Adam thought family-centred care was the same care as group therapy. Only Hanaa and Rasha showed a relatively close understanding of the meaning of FCC as the care concerned with the child's family. Nonetheless, all participants did not seem to recognise using the FCC approach in their own practice, though their reflections on clinical practice seemed to show the opposite. Their responses to the questions *"How do you think this concept differs from your own practice?"*, *"How do you practice family-centred care?"* is presented in the table below (table 12), using verbatim quotes from participants.

Participant	
Hanaa	<i>"Because mostly we the past years and up till recent we centre-based or school-based or community-based and we just ignore the family, where this is the first place needed to be care" Lines 794- 797</i>
Adam	<i>"We do not have it.. no.. we try.. we try here in the department we try depending on the place and ahhh the available resources" Lines 64- 66</i>
Maya	<i>"But here we do not have this.. we do not have it.." Line 182- 193</i>
Rasha	<i>"I mean, here if we talk about the sessions, 80% I focus on treating the patient, and 20% I focus on the families themselves. Like I feel that in this concept you focus more on the family...we are more patient-centred." Lines 705- 708</i>

Table 11 Physiotherapists responses

6.3.1.2 Different roles of care

This theme highlighted the different roles that the family played in the child's life and how the physiotherapists viewed it. All participants appeared to perceive the mother as the primary carer of the child, who is carrying the full responsibility of care and rehabilitation on her shoulders, whereas the father's role in care and involvement in rehabilitation was seen as limited. Even though all of the physiotherapists acknowledged the important role of fathers in care and its significance, Hanaa and Adam pointed out how the fathers' jobs and employment were an important barrier to such involvement. In fact, Hanaa and Adam believed that Saudi culture has an impact on the family dynamics regarding care roles as fathers were perceived to be the ones who work to earn money and support the family financially, whereas the mother accompanies the child at all times. Although all of the physiotherapists appeared to welcome the fathers' presence inside the rehabilitation setting, they revealed the different barriers to such involvement. Hanaa disclosed how the Saudi culture prevented fathers' entrance into a females-only setting, noting how this is seen as unacceptable to the mothers. While Maya felt that the limited working space that she had controlled the entry of fathers to the sessions. Rasha sensed that the fathers' involvement was limited to their presence with the child during treatment and to the child's attachment to the father.

Siblings were thought to play an important role in the rehabilitation of children with disabilities. Indeed, all of the physiotherapists saw siblings as helpers and motivators to the affected child. Their presence was considered a facilitator of rehabilitation, making the session more enjoyable and thus promoting the child's improvement. However, Hanaa emphasised that sometimes siblings' negative attitudes when assisting the child with a disability are perceived as interference that adversely affects the child's condition. This could be demonstrated by a case in which a child is able to walk after receiving treatment, but his siblings, instead of supporting and improving his walking, would prefer to transport him in a wheelchair rather than walking him to the car, thus interfering with Hanaa's practice as perceived by her.

6.3.1.3 Limited role of support

All of the participants showed an interest in helping families financially; however, this support seemed to be not within their authority as they had to refer the children to a social worker every time they needed financial support. According to Maya, the extent of support given was thought to be limited to her job description as she felt herself to have a limited authority to refer. This point was also raised by Rasha. Regarding the emotional support offered to parents by physiotherapists, Maya and Hanaa chose to direct the families or mothers to a psychologist for further emotional support and to help them understand and accept the child's condition. Alternatively, Rasha supported the mothers emotionally and psychologically by promoting and encouraging family members to get involved in the child's care to lift the burden off the mother's shoulders. In order to give families hope regarding the child's condition, Adam, Maya and Rasha used the stories of other cases of anonymous children with disabilities who improved as a way to provide parents with the emotional support they needed with the child's rehabilitation.

6.3.1.4 Communication as very important

This theme appeared to be important as all the physiotherapists highlighted its necessity in rehabilitation. They described how communication was related to many aspects of rehabilitation and care, and directly linked to information sharing, support, parents' empowerment, awareness and education. Hanaa believed that communication was a positive rapport-building tool between her and the parents that helped her understand the family's social status and helped families share their concerns openly. Adam considered the communication between him, the child's family and the medical team treating the same child as very important, as it ensures collaboration between them all, thus facilitating the child's rehabilitation. Maya felt that communication and information sharing, in the form of providing explanations when needed and following up with parents on the child's condition and treatment, were facilitators to parents'

understanding better. Similarly, Rasha felt that communication ensured parents' compliance with the exercises given to them, thus reaching her desired goal with the child's condition.

6.3.1.5 Parents' Education and Awareness

This theme was revealed from the narratives of all four physiotherapists and is believed to impact upon the parents' understanding of, acceptance of and compliance with treatment, the child's care and rehabilitation and progress. Hanaa felt that parents' lack of awareness and knowledge about the child's disability prevents them from accepting the child's condition. This has resulted in parents having unrealistic hopes and caused what Hanaa considered to be an interference to her practice as parents questioned her way of treatment, thus obstructing her care. Adam and Maya also perceived parents' lack of acceptance of therapy as a barrier to rehabilitation. Both explained how this impacted parents' compliance with the rehabilitation and continuity of care, causing an interruption in treatment and negatively affecting the child's condition. Rasha inferred that a lack of awareness about the importance of physiotherapy has also led to parents' ignorance in terms of supporting care and not making sound decisions. Indeed, she believed that the parent's educational level played a significant role in shaping their opinions, views and beliefs of a particular treatment, leading to decision misjudgment in some instances. Despite this, all of the physiotherapists' seemed to view themselves as obligated to educate parents, helping them understand the importance of physiotherapy and guiding them throughout the rehabilitation process by providing them with the support they needed. Adam believed that this could build parents' trust and faith in physiotherapy, which in return would reflect on the child's care and their commitment to treatment.

6.3.1.6 Parents Empowerment

The empowerment of parents was revealed in all four narratives and was experienced in different ways. Hanaa defined empowerment as boosting mothers' self-confidence to properly perform their children's exercises by providing them with hands-on experience rather than them passively watching how the treatment was performed. Similarly, Maya and Rasha perceived empowerment as enabling mothers to do the exercises for the child at home by ensuring their full understanding of them. Additionally, Rasha felt that helping mothers face the negative stigma about a child's disability was a form of empowerment that enabled them to be more assertive when dealing with such negative comments, thus giving mothers the push needed to continue with the child's care. Adam felt that encouraging and allowing the parents to get involved in the child's care was one way of empowering them and increasing their awareness of the child's condition and rehabilitation. In fact, Adam and Maya considered parents as partners rather than parents of children with disabilities and emphasised the important role they played in rehabilitation.

6.3.2 Physiotherapists' Unique Experiences

This section demonstrates the unique idiographic experiences that the four physiotherapists have described. Hanaa was unique in describing her culture, her attachment to it and its impact on her morals and clinical practice when dealing with children with disabilities. Although she seemed to welcome FCC as an approach to clinical practice, promoting family involvement, she also described how Saudi culture acted as a barrier to the ideal FCC because it prevented the proper participation of fathers and other family members in rehabilitation. Hanaa touched on the impact of the separation on the parents' role in the child's care within Saudi and the mother's frequent dependence on nannies for a child's rehabilitation, all of which she felt was a cultural barrier. Hanaa also believed the Saudi culture was culpable for a negative stigma about childhood disability, which she found similar to the effect of her Indian culture. She described how this

stigma had an impact not only on the families but also on the child's self-image and self-esteem. Thus, she emphasised the importance of integrating the child with a disability into his community instead of segregating him to promote better care and family involvement.

Adam's narrative reflected his strong faith and the religious beliefs he held; it was evident that this faith influenced his behaviour in terms of the support he gave to parents in order to overcome the challenging journey of a child's disability. Adam pointed out some of the barriers that disrupted the session, which he seemed to acknowledge and accept. This included the child's fear of medical uniforms and unfamiliar surroundings as some children would cry and be terrified. Adam, however, was concerned about parents' interference when a child cried, which he perceived as unreasonable and interfering with the session.

Maya provided a unique perspective on the significance of her role in educating the siblings of the child with a disability about their condition, highlighting how this could resolve any jealousy, which she believed was a barrier to the child's rehabilitation and care. Lack of power to refer was a vital theme drawn from Maya's narrative as she highlighted the impact it had on her abilities to help the child in a way that was in his/her best interest as she felt restrained from providing the needed support. The lengthy referral process appeared to impact Maya's clinical practice directly as it caused delays in the rehabilitation process and interrupted the child's progress. Thus, she emphasised the importance of having the autonomy to refer and efficiently collaborate with the other medical staff in order to treat the child and facilitate the rehabilitation process.

Rasha stressed the importance of collaboration between physiotherapists, both to her practice and to the children. Peer interaction facilitated rehabilitation sessions for children by serving as a source of motivation. In addition, Rasha highlighted how the negative stigma associated with childhood disabilities affected the opinions and views of parents regarding physiotherapy, leading to parental doubt and depression. Rasha seemed to find this matter to be irritating, which had an influence on her practice and on the child's development.

6.3.3 Conclusion

This section revealed six overarching themes drawn from the physiotherapists' shared experiences of family-centred care for the rehabilitation of children with physical disabilities in Saudi Arabia, all of which are related to one another and are considered essential components of FCC. It also highlighted each physiotherapist's unique experience with rehabilitation and the most prominent themes raised from their individual narratives. It can be shown from these experiences the different roles of care that family members have and how the culture has an impact on role distribution, causing mothers to adopt the most prominent role of care. The siblings' role in rehabilitation was also perceived as an important one that helped reduce the burden of care on the mothers and facilitated physiotherapy sessions as siblings were helpers for the physiotherapists. Communication was revealed to be an important theme that impacted upon many aspects of rehabilitation, including parents' awareness, education and the provision of information, guidance and support, which all directly affected the child's progress. The limited roles that physiotherapists have in supporting the families financially and emotionally were also reflected in their narratives, which was thought to be something that needed improvement.

6.4 Shared Experiences Within Centres

This section provides an account of the mothers' and physiotherapists' shared experiences within each centre, illustrating the differences, commonalities and patterns of participants' narratives to highlight their shared experiences and meanings of family-centred care.

6.4.1 Shared Themes: Similarities and Differences of Participants Superordinate Themes

After analysing the descriptive findings of each mother's and physiotherapist's idiographic experiences and highlighting the patterns from their individual narratives, the analysis moved to look for patterns within centres. The shared themes that were evident within each of the mothers' and physiotherapists' interviews from each centre are presented in the following Figures (Figures 4,5,6 and 7). The shared experiences within centres will be discussed in order, one centre at a time. The dark blue colour represents the superordinate themes, the lighter blue colour represents the subordinate themes, the very light blue colour represents the subthemes and the blue filled squares represents the similarities between themes.

6.4.1.1 *Salamago Centre*

This charitable organisation provides specialised services to children with disabilities from birth to 12 years. It was first established in 1981 and became one of the largest organisations in the Arab world. It provides care for children with disabilities and offers free education, rehabilitation, and curative services for more than 4000 children annually. The Centre provides various medical services, including physiotherapy, occupational therapy, speech and language pathology therapy,

mental clinics, intensive therapy and early intervention therapy. It also offers other services like education, awareness and social services. Figure (4) shows the shared themes between the physiotherapist and mother at Salamago Centre, highlighting the commonalities in experiences.

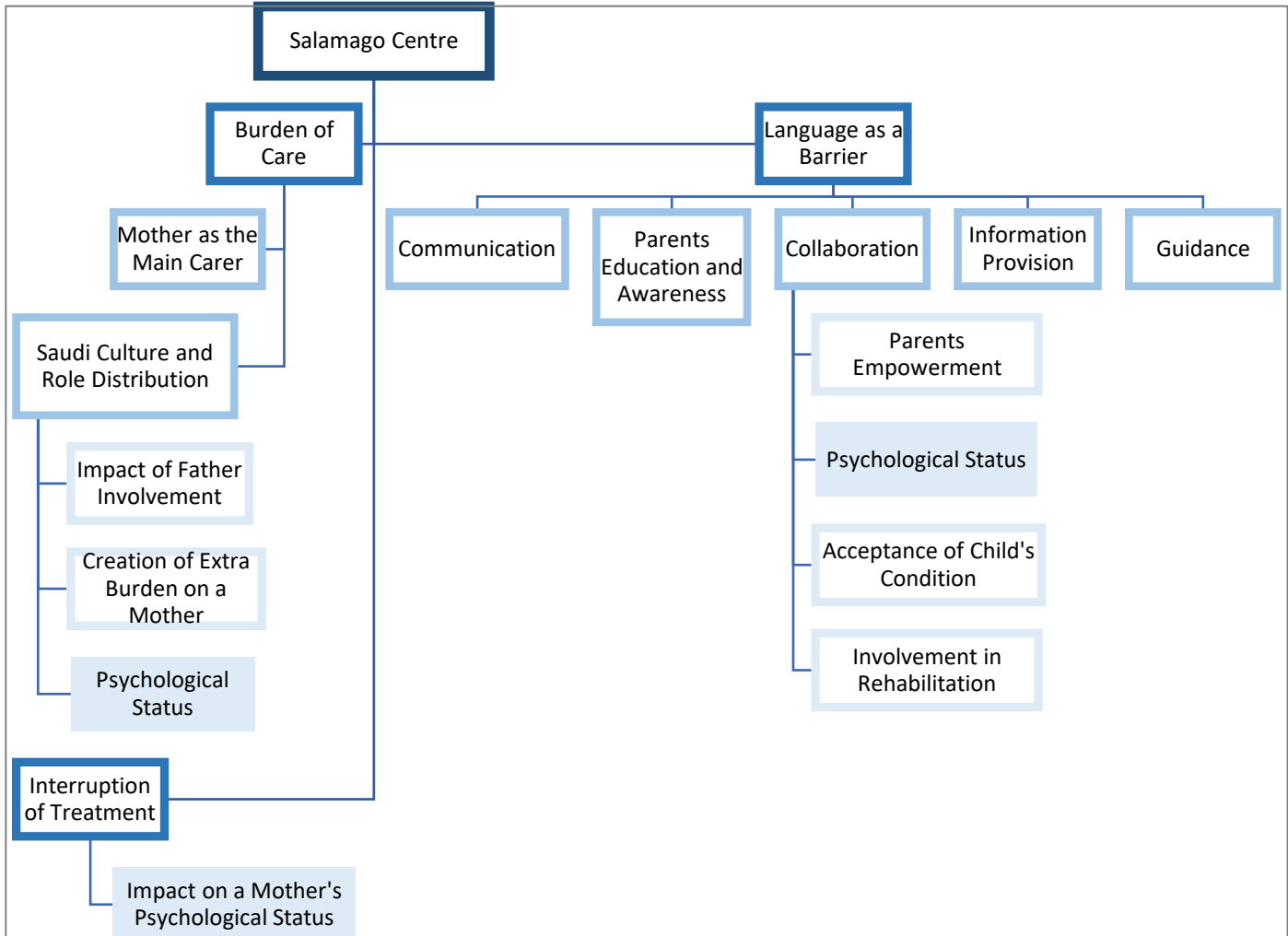


Figure 4 Salamago Centre shared experiences

There were three main themes shared by the physiotherapist Hanaa and mother Wed in terms of their experience in Salamago Centre, which were 'burden of care', 'language as a barrier' and 'interruption of treatment', all of which have had an impact on the mother's psychological status. Mothers were perceived by Hanaa and Wed as the child's primary carer and carried the burden of care because the Saudi culture impacted the distribution of caring roles among parents and the father's involvement in rehabilitation. The language was another important theme revealed

from both experiences, as language differences between the physiotherapist and mother were thought to be barriers to childcare. In fact, it was described as limiting to Hanaa's clinical practice in terms of communication, information sharing, collaboration, guidance, parental education and awareness. She believed these elements impacted upon parents' empowerment, their acceptance of the child's condition and involvement in rehabilitation as well as, in some cases, causing interruption of treatment, as in the case of Wed.

6.4.1.2 Mulberry Hospital

This governmental hospital provides free care and medical services to women and children from birth until the age of 14. It has a physiotherapy department only, which provides care to women prenatally and postnatally (inpatients), rehabilitation services to children with neural, muscular, and orthopaedic conditions and physical disabilities. The physiotherapy department works with the social worker department and education clinic to provide support, awareness and education to parents needing it. Figure (5) displays the shared themes between the physiotherapist and mother at Mulberry hospital, highlighting the commonalities in experiences.

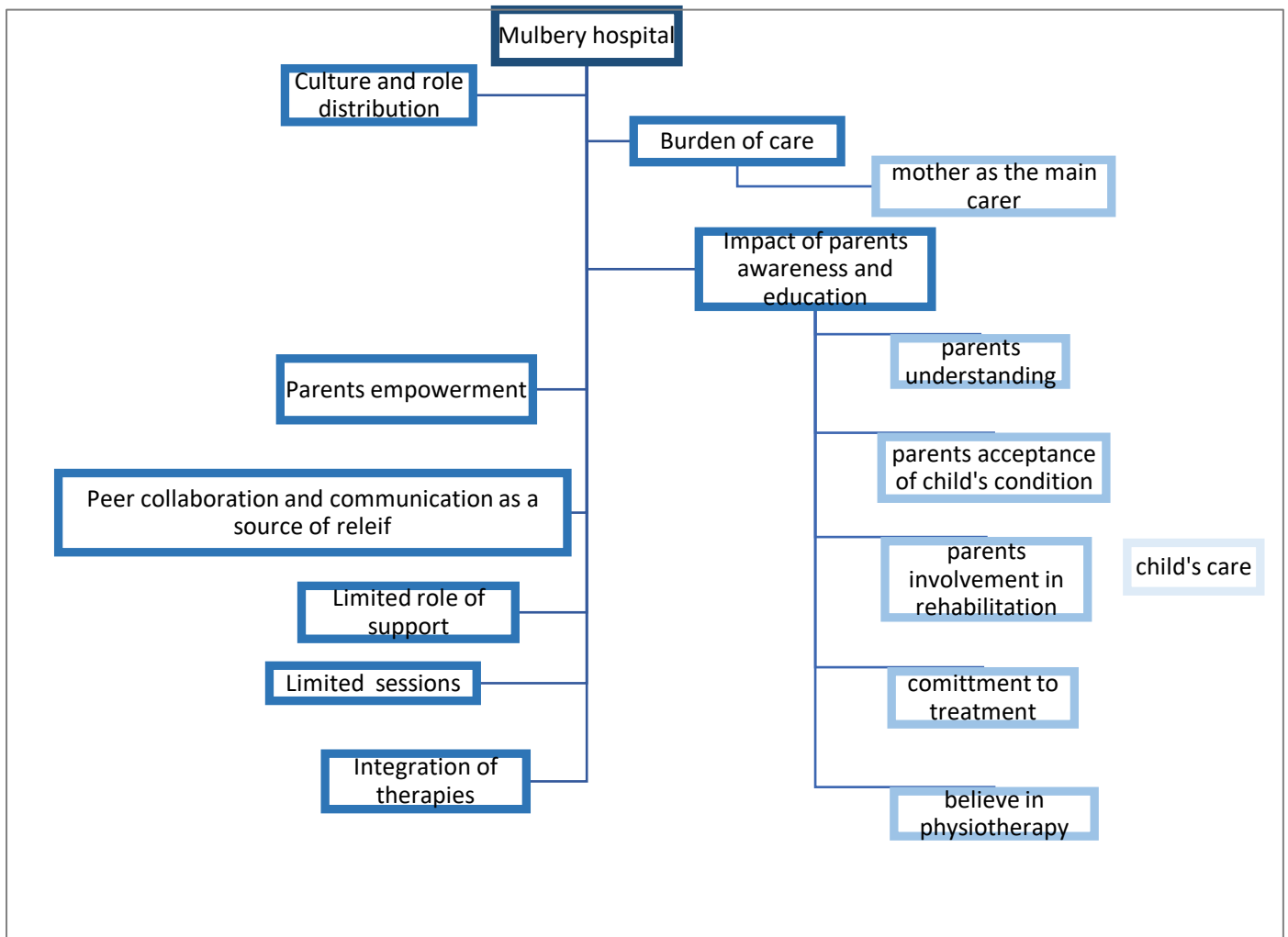


Figure 5 Mulberry Hospital shared experiences

The main themes shared by the physiotherapist Adam and the mother Mona were *'burden of care'*, *'culture and role distribution'*, *'impact of parents' awareness and education'*, *'parents empowerment'* and *'peer collaboration and communication as a source of relief'*. Adam and Mona shared the themes of the burden of care and the role that culture plays in role distribution, reflecting how they both perceived the mother as the child's main carer within the Saudi context. Additionally, the impact of parents' awareness was one of the prominent and important themes shared. It was directly related to parents' understanding and acceptance of the child's condition, belief in physiotherapy and commitment to treatment. To Adam, parents' empowerment and enabling them to get involved in the child's rehabilitation were believed to affect the extent of engagement in therapy and their commitment to it. The theme "peer collaboration and communication as a source of relief" revealed how the collaboration and communication between Adam and other healthcare workers and the collaboration and communication between Mona and other mothers were considered sources of relief that facilitated the child's care and rehabilitation.

6.4.1.3 Whoville Hospital

This governmental hospital provides medical care and services to pregnant women and children free of charge. The hospital has a relatively small physiotherapy department that offers rehabilitation services to children with disabilities like Down Syndrome and physical disabilities, including CP. The department works with other governmental hospitals to provide children with the necessary assistive devices and works with the social worker department in the same hospital to financially support children and their families. Figure (6) reveals the shared themes between the physiotherapist and mother at Whoville Hospital, highlighting the commonalities in experiences.

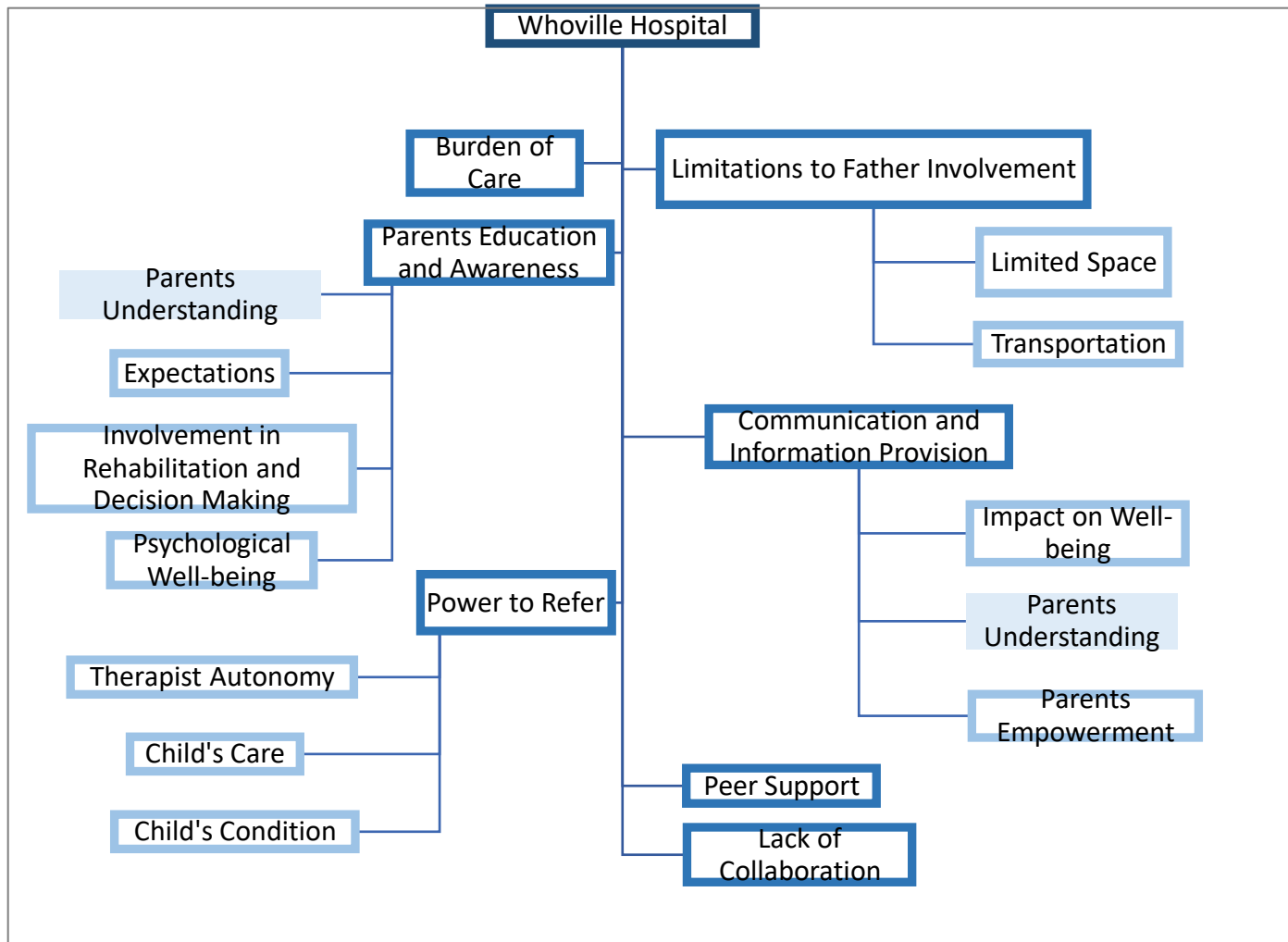


Figure 6 Whoville Hospital shared experiences

Seven main themes were shared by physiotherapist Maya and mother Basmah’s in terms of their experience of FCC. These were ‘burden of care’, ‘limitations to father involvement’, ‘communication and information provision’, ‘parents education and awareness’, ‘power to refer’, ‘lack of collaboration’ and ‘peer support’. Both Maya and Basmah highlighted how the mother had the most prominent role in the child’s rehabilitation, carrying the full burden of care on her shoulders. Additionally, they revealed the different barriers to the father’s involvement in treatment, including transportation and having limited treatment space, which they felt had created an extra burden on the mother. The communication and information provided were believed to be related to parents’ understanding and awareness and to impact upon their

empowerment, involvement in rehabilitation and the decision-making process and psychological well-being. The power to refer was a unique theme for Maya and Basmah, reflecting the impact of the loss of authority to directly refer the child to the support necessary for the child's progress and rehabilitation. Both Maya and Basmah believed that this lack of power to refer reflected the lack of collaboration between the healthcare workers treating the same child and was considered an essential issue as it created a barrier to the child's treatment. They felt that the peer support between the mothers themselves was a helpful form of emotional support that enabled mothers to have faith in the child's rehabilitation and improvement.

6.4.1.4 Roover Hospital

This governmental hospital provides medical care and services for various medical conditions, treating adults and paediatrics. It has a reasonably big physiotherapy department that treats outpatients and inpatients, both adults and paediatrics. It provides rehabilitation services to children with disabilities like Down Syndrome and physical disabilities, including CP. The department works with other governmental hospitals to provide children with assistive devices and the social worker department to financially support them and their families. Figure (7) shows the shared themes between the physiotherapist and mother at Roover hospital, highlighting the commonalities in experiences.

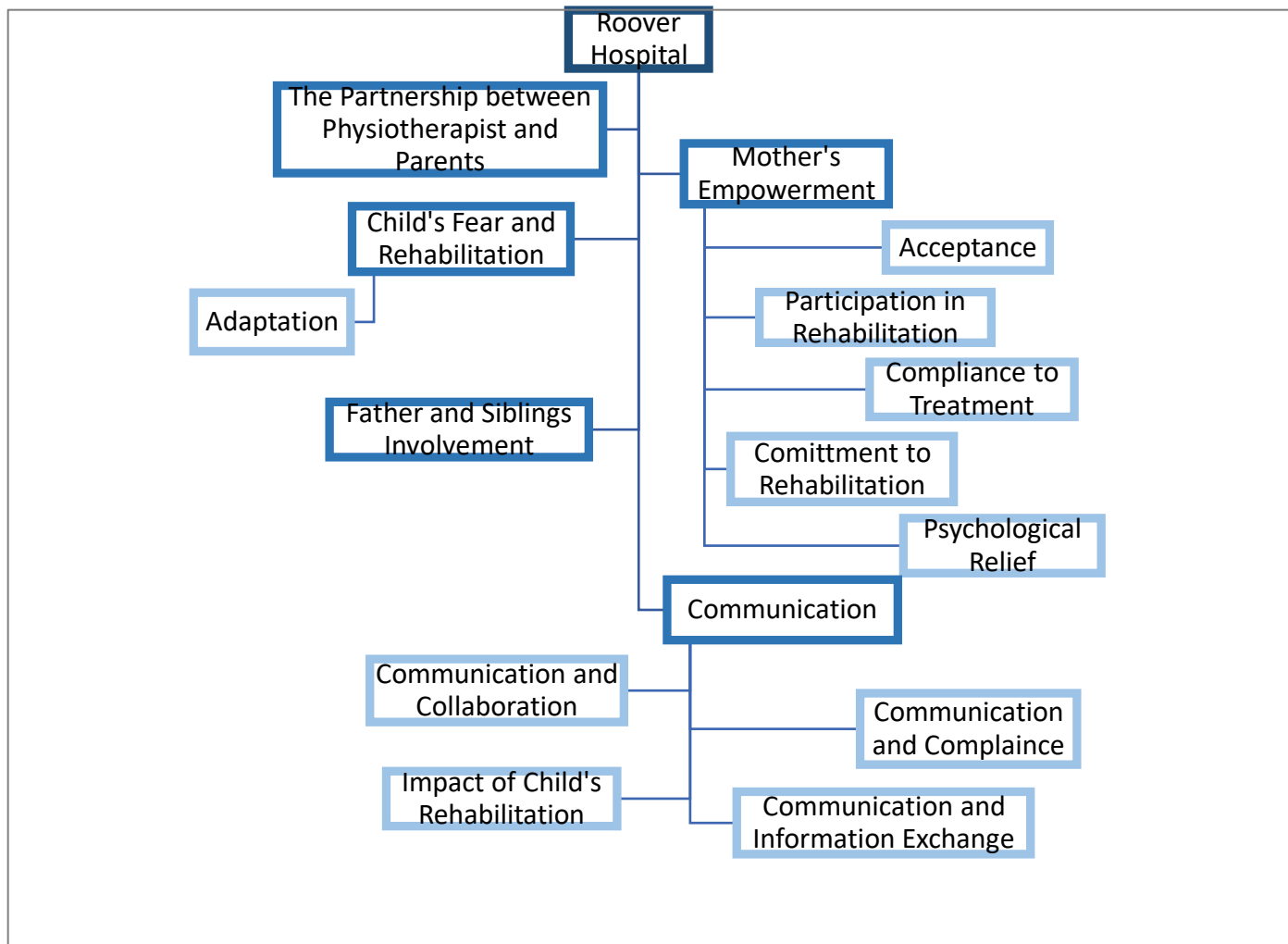


Figure 7 Roover Hospital shared experiences

There were five main themes shared by physiotherapist Rasha and mother Salma in terms of their experience. These were *'the partnership between physiotherapist and parents'*, *'mothers' empowerment'*, *'communication'*, *'fathers' and siblings' involvement'* and *'child's fear and rehabilitation'*. Rasha and Salma considered the partnership between the physiotherapists and parents important to enable parents' empowerment, which in turn affected parents' acceptance of their child's condition, participation in rehabilitation and commitment to treatment, and the mother's psychological relief. Communication was also considered an important theme to both Rasha and Salma. It was related to information provision and collaboration between the physiotherapist and parents and the parent's compliance with treatment, all of which are thought

to impact a child's rehabilitation. The fathers' and siblings' role and involvement in rehabilitation seemed to be of great importance to both Rasha and Salma; however, Salma's fear and lack of trust in other family members' abilities created a barrier to their engagement in rehabilitation and care. The child's fear of new surroundings and medical uniforms was an important theme to both Rasha and Salma as they felt it significantly impacted the child's adaptation and session flow.

6.5 Conclusion

This section revealed the themes from shared and unique experiences of the mothers and physiotherapists as well as themes shared in each Centre. The analysis of shared experiences has shown five overarching themes drawn from participants' narratives. These overarching themes, which are believed to be essential components of family-centred care and interrelated are all influenced by the cultural context of Saudi. These overarching themes will be explored in the ensuing discussion chapter, where the following superordinate themes and subordinate themes will also be discussed:

1. Current status of family-centred care within Saudi Arabia
 - Understanding of family-centred care
 - FCC as 'absent' a shared perception
2. Roles of care and family dynamics in Saudi
 - Burden of care
 - Reliance on the mothers
3. Communication as the cornerstone to family-centred care
 - Communication between physiotherapists and parents
 - Communication between parents themselves

- The impact of communication on parents' understanding and awareness of child's rehabilitation
 - Barriers to communication
4. The provision of support
- Emotional support
 - Financial support
 - Information provision as a source of support and relief
 - Limited authority to refer as a barrier to support.
5. Culture as a barrier to father's involvement

CHAPTER 7 - DISCUSSION

7.1 Introduction

This study examined how physiotherapists and mothers in Saudi Arabia perceive and experience family-centred care in the rehabilitation of children with physical disabilities. The lived experiences and perceptions of a participant sample of mothers and physiotherapists in Saudi Arabia were investigated in order to gain insight into the provision of family-centred care within this context. As detailed in the methodology chapter (Chapter 4), this was accomplished through the analysis, description, interpretation, and understanding of the experiences of physiotherapists and mothers using interpretative phenomenological analysis (Smith et al. 2009). This approach, which is grounded in interpretive phenomenology (Heidegger 1996), employs the double hermeneutic method for data collection, wherein the researcher seeks to gain insight into the participants' interpretations of their experiences (Smith et al. 2021). Consequently, these experiences were interpreted through the perspectives and understanding of the participants themselves.

This process facilitated the interpretation of the meaning of participants' experiences in order to ascertain whether and how FCC was enacted by mothers and physiotherapists within clinical rehabilitation practice in Saudi Arabia. Moreover, it provided an opportunity to reflect more deeply on the experiences gathered, thereby enhancing the understanding of the current state of FCC in the hospitals and centres included in the study. This examination allowed for the identification of potential improvements, modifications, or clinical implications that may be required in the rehabilitation services provided to children with disabilities. As a result, it will also contribute to the development of family-centred rehabilitation services that address the needs of children, their families, and physiotherapists.

Following the presentation of results on idiographic levels (see Chapter 5) and the cross-analysis of the shared experiences of both mothers and physiotherapists (see Chapter 6), the aim was to explore how participants comprehended, perceived, and interpreted their own experiences in

light of the existing literature. Consequently, this chapter offers an overview of the research results presented in this thesis, examining them in relation to the current literature on family-centred care. This approach serves to contextualise their meaning, connect them to the wider body of knowledge on the subject, and situate them within the broader societal context and, more specifically, within Saudi culture.

7.2 Recap of Research Question, Aims, and Objectives

For the purpose of contextualising this chapter, the research question and aims, and objectives are reinstated as follows.

7.2.1 Research Question

The following research question guided this study:

What are the physiotherapists' and mothers' lived experiences and meanings of family-centred care for the rehabilitation of children with physical disabilities in Saudi Arabia?

7.2.2 Research Aim

The aim of this research was to explore the physiotherapists' and mothers' lived experiences and meaning-making of family-centred care for the rehabilitation of children with physical disabilities in Saudi Arabia.

7.2.3 Research Objectives

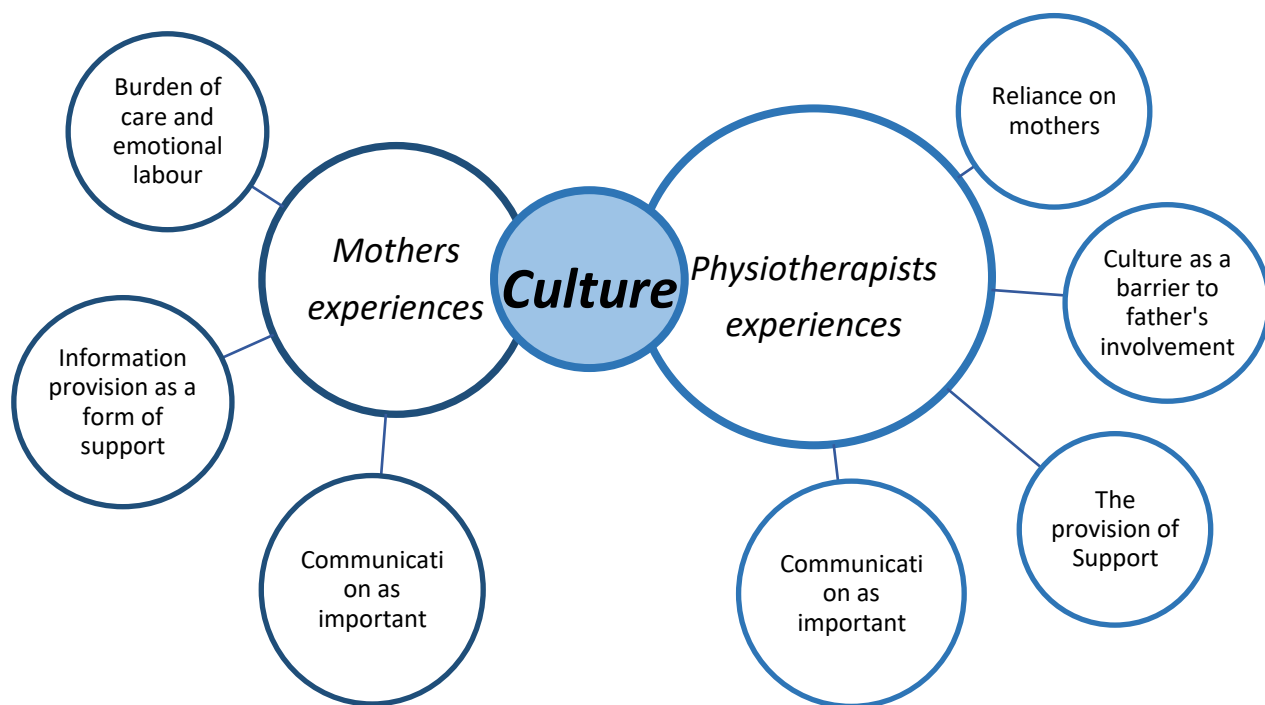
- To explore the personal lived experiences and meanings of physiotherapists and mothers of children with disabilities concerning family-centred care
- To explore the mothers' perceptions and meanings of the care received from physiotherapists in the context of family-centred care
- To explore the physiotherapists' perceptions and meanings of the care they provide in the context of family-centred care

7.3 Placing Current Research on Family-Centred Care in the Wider Context

In light of this study's findings and based on the analysis of shared experiences, this section highlights the meaning of the experiences of both mothers and physiotherapists. Family-centred care within Saudi Arabia is significantly influenced by the cultural context of the country, which impacts every aspect of parents' and physiotherapists' experiences with FCC, as well as its provision. The cultural context of Saudi Arabia differs considerably from that of other countries, particularly Western nations where FCC originated. Thus, such comparisons are not entirely accurate, as physiotherapy and the different models of healthcare in Saudi Arabia currently holds a different position compared to its Western counterpart, where it has been developed and integrated into the healthcare system.

Although FCC was not explicitly recognised as a concept in this study, some of its principles were embedded within the cultural values and codes of conduct (SCFHS 2019) in the Kingdom. That suggests that certain FCC elements are implicit in the clinical practice of physiotherapists rather than being formally acknowledged. Though the participants in this study experienced FCC to some extent, they were somewhat unaware due to a lack of understanding of the concept, leading them to believe they did not experience FCC.

Contradictions emerged in the findings, all of which are considered significant and unique, and contribute to the understanding of the family-centred approach to physiotherapy care in Saudi Arabia. Since FCC is a culturally constructed approach to care, all the findings discussed in this chapter, including the contradictions, establish the groundwork for developing what family-centred care might encompass in Saudi Arabia. As Watts et al. (2014) noted in their systematic review, a family-centred model of care may differ in its formulation, application, and outcomes depending on the population and setting in which it is implemented. As previously mentioned, culture played a substantial role in shaping experiences of FCC, with factors such as gender segregation, family dynamics, and the different roles expected of each family member contributing to the concept. Moreover, this study emphasised the importance of maintaining communication and respecting the mother's wishes in a manner that makes them feel supported by healthcare professionals and family members. Additionally, it highlighted the need to respect the preferences of each family member and the extent of parental participation they desire. Thus, all of the aforementioned points will be discussed meaningfully, as illustrated in the diagram below (see Figure 7), to provide a clearer understanding of FCC, beginning with the mother's experiences, followed by the physiotherapist's experiences, and concluding with the similarities and contradictions highlighted in the findings.



Similarities	Understanding of Family-centred care
	FCC, a shared perception of 'absence'
	Communication as the cornerstone to FCC
	Language as a barrier to communication and support
	Limited authority to refer as a barrier to support
Contradictions	Level of Involvement and desires
	What is actually happening and what is perceived
	What is desired and what can be achieved

Figure 8 Discussion outline

7.4 The Mother's Experiences and Perceptions

7.4.1 The Burden of Care and Emotional Labour

This study highlighted the burden of care and emotional labour, referring to the emotional stress, pain, and various feelings experienced by mothers due to their children's disabilities and the process of becoming aware of and accepting them. The literature defines caregiver burden as the overall strain experienced by a caregiver over time when caring for a family member or loved one, which may include a range of negative responses and feelings (Liu et al. 2020). The burden of care in this study encompassed feelings of shock, denial, fear, and confusion as a result of sociocultural influences related to Saudi culture, profoundly impacting the mothers' desires and involvement in the child's care and thus participation in FCC.

❖ *Fear of the unknown*

Mothers described various feelings of fear and confusion related to their child's condition and diagnosis, such as feeling 'scared' about the negative emotions they experienced. Some described it as an unexpected catastrophe that profoundly affected their lives. It was poignant to observe how mothers reacted and felt when they learnt of their child's disability; however, similar reactions have been reported in previous studies. In Saudi Arabia, Alariefy (2016) identified that new mothers tend to exhibit high levels of despair and disappointment when their hopes of having a healthy child are not fulfilled. This included shock, denial, grief, and frustration as a result of caring for a child with a disability, as reported by Madi et al. (2019), where the diagnosis of CP was described as "*the end of the world*" (p. 7) by mothers. Other parents referred to the experience of having a child with a disability as being in a fire, describing that no one will be able to understand the difficulties they are facing except those who have been there themselves (Alariefy 2016). Parents may feel this way as they seek to meet social expectations of

raising a healthy child, but they find that they are not able to meet such expectations due to the birth of a child with a disability. From a cultural perspective, mothers' aspirations for the future of their children and their improvement reflect a desire and an expectation that their children with disabilities might lead a healthy life, regardless of the severity of their condition (Madi et al. 2019). This might affect what the parents desire and wish for their children with disabilities, in terms of rehabilitation services and family involvement, thus impacting the possible provision of FCC within the context of Saudi Arabia. Furthermore, it can be inferred from this study that the mothers' aspirations may have been motivated by their sense of responsibility and guilt towards the affected child, which was an issue raised throughout this study.

❖ *Feelings of guilt and accountability*

The sensation of being accountable and responsible for their child's condition prompted some mothers to sacrifice their career and life choices in order to care for their children with disabilities, as they regarded this as their maternal obligation (see pp. 155 and 174). Mothers felt compelled to abandon their personal preferences for the benefit of their children and family responsibilities. Perhaps it is not as relevant for them to work as it is for their husbands and this may be due, in part, to the cultural norms of Saudi Arabia, where women are encouraged to remain at home to raise their families, whilst men are urged to work and provide for them (Hatch and Posel 2018). A person's culture is believed to determine the roles they assume in society, as well as the expectations that shape their attitudes and behaviours, as suggested by Matsumoto and Hwang (2019).

In Saudi Arabia, the impact of culture on parents' emotional experiences whilst caring for children with disabilities has not previously been examined within the family-centred care literature; however, it has been explored by other medical professionals. For instance, Madi et al. (2019) discovered that cultural influences directly affected how mothers felt about their children with disabilities, resulting in feelings of guilt. Additionally, culture and religion strongly influenced participants' perceptions and beliefs about disability in Saudi Arabia (Banaser et al. 2017), where

some parents viewed it as a blessing from Allah intended to test their patience, and others viewed it as a punishment (Madi et al. 2019). In this study, mothers' feelings of guilt originated from being part of Saudi society, where giving birth to a child with a disability is considered a parental failure, and mothers are held responsible for their children's condition (Alariefy 2016). Moreover, the community's and individuals' attitudes towards disability and stigmatisation contributed to mothers' sense of blame, shame, rejection, and exclusion (Madi et al. 2019), as they avoided social gatherings to protect themselves from such stigmatisation (Nazzal and Al-Rawajfah 2017).

❖ *Intensive mothering*

Despite the negative feelings exhibited by mothers, their ideology of intensive mothering was evident. Intensive mothering is an idiom that is endorsed by both men and women. It positions mothers as the preferred caregivers responsible for their children's emotional, social, cognitive, and physical development (Hays 1996). Despite the idiom's origins dating back to 1996, it remains influential and has been adopted by numerous cultures. Forbes et al. (2020) suggest that intensive mothering is a widely accepted norm, with women holding similar beliefs on the matter regardless of race, ethnicity, relationship status, social class upbringing, number of children, or employment status.

In this study, the mothers' views about their responsibilities and roles in raising their children and families were influenced by their social environment. Saudi culture places a great deal of responsibility on mothers, including high expectations, reliance, and dependence on them. The traditional role of a mother has caused mothers to adopt such ideologies. Indeed, being part of a culture where overwhelming societal expectations and intensive mothering are promoted, where women are judged for their mothering attitudes and actions towards their children and families can present many challenges for mothers (Forbes et al. 2020).

This ideology also led mothers in this study to avoid pursuing careers or job opportunities out of fear that they would not be able to balance their caregiving roles at home and their duties at work. Al-Asfour et al. (2017) identified role conflict as a recurrent issue for working women in

Saudi Arabia, where they struggled to balance their work and family obligations whilst maintaining responsibility for domestic duties. This imbalance leads mothers to perceive themselves as performing poorly or not meeting society's expectations, resulting in them sacrificing career advancement for their families and children.

❖ *The big burden*

The ideology of intensive mothering seemed to have added burdens and challenges to mothers, assuming the 'ideal' mother is the one who prioritises her children's needs over her own career ambitions (Forbes et al. 2020). Basmah, for example, seemed to believe this notion as she took full responsibility for the child's condition and care, stating, "*The big burden is over my shoulders alone!*" (Line 238). This burden of care appeared to increase, particularly when the child is a child with special needs, where the mother must provide additional effort and attention, as mother Mona reflected on her own experience and explained how she felt "*especially when the child is a child with special needs.. he/she needs special care...*", "*so this requires effort from you as a mother, and you have other children and a husband and have to cook*" (Lines 207- 211).

In the Middle Eastern context, the burden of care has been raised by the literature about disability rather than family-centred care, as evidenced by the study of Nazzal and Al-Rawajfah (2017), who examined the lived experiences of mothers caring for children with disabilities using phenomenological methods. Continuous caregiving can disrupt a family's life when caring for and raising a child with a disability, as it is physically, financially, socially, and/or psychologically exhausting for them (Nazzal and Al-Rawajfah 2017). This means that parents of children with disabilities are feeling burdened and burnout by their caring responsibilities because it is so stressful, which has impacted their desires during rehabilitation and their participation in childcare.

Nazzal and Al-Rawajfah's (2017) findings were consistent with the findings of the present study, which indicated that families of children with disabilities appeared to incur psychological and emotional strain as a result of the child's presence. Since FCC is culturally constructed, it is

necessary to recognise and take into account the cultural context of families and the burdens of care that are entailed and caused by this context when considering such an approach to care. This will help healthcare workers appreciate the family's situation as a whole, which may affect their desire to participate in rehabilitation and caring duties.

It can be inferred from the preceding discussion that mothers raising children with disabilities are increasingly burdened by care and stress due to their role as caregivers, how they perform this responsibility independently, and the cultural expectations and responsibilities placed upon them. This has not been acknowledged in earlier physiotherapy literature but has been observed in other medical disciplines, such as nursing. For example, Purpura et al. (2021) found that parents caring for children with neurodevelopmental disorders experience significant stress, affecting their relationships, lifestyles, and activities. Over half of the participants reported moderate to high levels of stress, confirming the burden faced by parents (Purpura et al. 2021). In Saudi Arabia, Emam et al. (2021) revealed a negative correlation between parental stress levels and life satisfaction, indicating that stress was related to psychological difficulties. Parents with a child with a disability experience negative emotions and perceive life as a source of pain due to the stressors associated with their child's impairment (Emam et al. 2021).

These feelings have a profound effect on mothers' perceptions, meanings, and lived experiences of family-centred care and their experiences with childcare. In fact, the burden of care, negative emotions, and intensive mothering all contribute to mothers feeling overloaded by their responsibilities. In the case of the current study, this can negatively impact the provision of FCC, where a partnership is encouraged, leading to an unequal partnership in relationships.

Considering the potentially profound effects of the 2030 vision, the traditional roles of caregiving and the ideology of intensive mothering may undergo a transformation that relieves pressure on mothers. In fact, the 2030 vision focuses on empowering women in both professional settings and broader societal contexts. This includes increasing the number of women in the workforce, providing women with more training and educational opportunities, reducing gender-based discrimination, and creating a more equitable society (Vietor and Sheldahl-Thompson 2018).

Consequently, as a result of this progressive shift, parental duties and care roles could become more shared between both parents, thereby reducing the burden of care on the mother.

Given this context, it is crucial to address the challenges mothers face and support families, ensuring that family-centred care benefits not just the child but the entire family's well-being.

7.4.2 Information Provision as a Source of Support and Relief

In this study, mothers regarded the exchange of information between themselves, physiotherapists, and other parents as a source of support, that is essential for the child's care, mothers' understanding, and fathers' involvement. Despite the importance of providing information about a child's condition, progress, and future prospects, the study found that information was not provided sufficiently, as reflected in the narratives of mothers. Indeed, mothers expressed concern about their inability to access reliable information when necessary, and the theme '*I want more information*' was highlighted through their experiences (see Chapter 6), which impacted their participation in the care, decision-making, and rehabilitation of their children.

The literature has discussed how a lack of information has limited parents' ability to seek the necessary support and make informed decisions regarding the service (Stefansdottir et al. 2015). In cases where information was not presented in a timely manner, concealed, lacking, or delivered too quickly or in complex language, parents were unable to understand and participate in the decision-making process equally (Hill et al. 2017). Hill et al.'s (2017) findings are in line with the outcomes of the current study, in which mothers sought additional resources, such as the Internet, and other mothers when physiotherapists failed to provide information or when the information was insufficient. The reliance of mothers on various resources to acquire information indicates that their informational needs were not met as they highlighted their strong desire to obtain knowledge and emphasised the significant influence this information has on their comprehension and involvement in their child's treatment.

In the context of family-centred care, the lack of information offered to families is an ongoing concern that has been addressed by multiple studies in the literature, revealing shortcomings in the provided services. In prior literature (Garant et al. 2002; Dickens et al. 2010; Pickering and Busse 2010; Morgan and Tan 2010; Schreiber et al. 2011; Arnadottir and Egilson 2012; Saleh and Almasri 2013; Myrhaug et al. 2014; Wang et al. 2014; Sršen et al. 2014; and Stefansdottir et al. 2015), information provision has been demonstrated to be an aspect of care that is lacking, as evidenced by the perceptions of both parents and healthcare workers. Pickering and Busse (2010), for instance, highlighted barriers to providing accurate information to parents, where sometimes written information was difficult to comprehend as it was filled with medical jargon that was not easily understandable, and sometimes parents were unable to access the information needed. Similarly, Manzuma et al. (2021) explain how interpreting specific medical terms can be difficult even for highly literate caregivers, which explains why parents in their study valued verbal information for better conveying their children's treatment and progress. The findings of Pickering and Busse (2010) and Manzuma et al. (2021) are consistent with the findings of the current study, which indicated that some mothers avoided pursuing information and communication from physiotherapists as they did not want to engage in a conversation that might not be understandable due to the language used, as was the case with Basmah (see p. 177).

In recent years, studies such as (Molinaro et al. 2017; Kang et al. 2017; Terwiel et al. 2017; Shevell et al. 2018; McManus et al. 2019; and Antunes and Vaz 2021; Manzuma et al. 2021; Poojari et al. 2021) have demonstrated the persistence of the issue of inadequate information provision. Additionally, these studies have discovered various associations between parents' sociodemographic characteristics and the level of information provision, which contrasts with this study, where such associations were not revealed. This is primarily because these associations have not been adequately examined since the main objective of this study was to determine the meanings and interpretations of the experiences of the mothers and physiotherapists'. It is evident from the preceding explanation that the lack of information is not limited to a specific culture, as studies conducted in other cultures have also presented this finding. Instead, factors such as insufficient resources, time constraints, and therapists' busy

schedules (Srsen et al. 2014; Poojari et al. 2021) have hindered therapists from addressing parents' requirements for access to information and knowledge about their children's conditions.

In line with prior research, the mothers' informational needs in this study varied, with some seeking general information about their child's status, progress, and future, whilst other mothers requested detailed information regarding the child's rehabilitation schedule, advice on where to find help, and tips on how to connect with other mothers. Within the context of family-centred care, the provision of information to parents is one of the main principles, where emphasis is placed on the necessity to provide families with accurate, unbiased, and helpful information on a regular basis. Therefore, it is essential to evaluate these differences in order to tailor information to the specific needs and preferences of each family, which will enable them to participate in the child's care and decision-making.

Indeed, it has been found that high-quality information tailored to children's developmental needs and their parent's literacy level is the most commonly reported facilitator of paediatric shared decision-making (Boland et al. 2019). Furthermore, accurate and relevant information may facilitate parents' perceptions of the skills and knowledge needed to manage caregiving and parenting challenges effectively (Salvador et al. 2019). By having access to precise information, the mothers in this study may have been able to better understand and overcome the challenges they experienced after child's birth, which led to this burden of care. Consequently, they would have had a more positive experience with childcare and rehabilitation, as well as been more engaged in shared decision-making and the collaboration that family-centred care fosters.

7.5 The Physiotherapist's Experiences and Perceptions

7.5.1 Reliance on Mothers

Whilst mothers have highlighted the care burden they encountered as primary caregivers, physiotherapists in the study corroborated this perspective, identifying the mother as the child's

primary caregiver who played a vital role in his/her life. For instance, Maya described how she regarded the mother as the child's primary caregiver and, as a result, dedicated a substantial amount of time and attention to her: *"We focus mostly on the mother"* (Line 169). The mothers' continuous commitment, responsibility, and care towards their children appeared to reinforce these perceptions and notions that mothers are the primary caregivers. As Adam elaborated, *"The mothers are more caring because they are always with the child with a disability..."* (Line 250). The reliance on mothers and the expectations and responsibilities placed upon them by culture were thought to contribute to the increased burden of care and stress on mothers raising children with disabilities, which affected their experiences with childcare. Although Saudi Arabian culture fosters and emphasises the importance of family relationships within the framework of an individual's life and strong family relationships are valued and crucial in individuals' lives (Al-Saif 1991). Within the context of FCC, this dependence on mothers can act as an impediment to the active participation of fathers, male caregivers, and other family members, thus, on FCC provision, where the emphasis is put on the whole family around the child.

7.5.2 Saudi Culture as a Barrier to Fathers' Involvement

The physiotherapists raised the concern that cultural barriers impeded fathers' participation in the care and rehabilitation of their children, which would affect the provision of family-centred care within the Saudi rehabilitation context. Due to gender roles that determine care responsibilities in Saudi Arabia, fathers have been excluded from participating in rehabilitation settings and childcare for many years, leading to a misallocation of caring roles. As Hanaa pointed out, Saudi culture played a role in limiting fathers' involvement in their children's lives by emphasising the idea that *"The father is just a provider so most of the things they do not know, even though parents mean father and mother"* (Lines 184-188). Despite the fact that Hanaa was a foreigner working in Saudi Arabia, originally from India, her views about Saudi culture were valid, as other physiotherapists, who are Saudi nationals, shared similar views. As Adam explained, the father is responsible for earning money whilst the mother is responsible for taking care of the

children: *"The father goes to work... go out and come back..."* (Lines 252-253), thus confirming this notion.

Caregiving is deeply rooted in traditional cultures, such as Saudi Arabia, where some men regard caring as a feminine duty, causing fathers to be less inclined to participate in the parenting process and the care of their children (Valizadeh et al. 2018). Participants in this study adhered to this notion of gender roles, as evident in Adam's quote. Furthermore, the conservative nature of Saudi society acted as a barrier to the potential provision of FCC, in which sex segregation is promoted in public settings. Healthcare facilities are adapted so that men and women are separated, with each gender occupying a separate section. Whilst such segregation is considered a cultural norm that preserves privacy for families, individuals, and women, it nevertheless poses a barrier to the involvement of fathers in clinical settings. For example, Adam emphasised the normality of such cultural norms by saying: *"You know Saudis and the Saudi society want privacy... they are a bit conservative..."* (Lines 68-71).

Male caregivers are compelled to assume a passive role in a child's care, even if they wish to be involved, due to treatment arrangements within rehabilitation facilities that place children aged 0-13 (both boys and girls) in female sections, which do not permit male entry. The profound impact of such cultural norms on the physiotherapists' clinical practices seemed to limit their desire to involve the entire family in the rehabilitation of children, thus restricting family-centred care practice. As an example, Hanaa expressed the following:

"Because we are the ones talking about the family importance in the treatment plan, and we are the ones who are restricting the fathers to go inside, because of the culture. The thing is the therapists or the experts do not have any issues with the fathers entering into the system, but this is a community, the house community where other mothers are there, other children are there, so this is a barrier." (Lines 384 – 390).

This quote demonstrated a positive attitude towards family involvement in physiotherapy care, which encouraged father engagement, family participation, and collaboration in the child's care process. However, this was impeded by the cultural barrier. As a consequence, this has led to a paradox between physiotherapists' desires and what can be achieved, resulting in a contradiction. Cultural norms continued to exert a significant influence on physiotherapists' practice, even despite their efforts to overcome this barrier. As an example, Hanaa explained the difficulty she encountered in integrating fathers into the rehabilitation setting by stating:

“So they cannot mingle all fathers, different fathers like in a mall, it is not possible here it is mainly because of the culture they are restricting the fathers from going inside” (Lines 393-395).

The confusion between beliefs and emotions was found to affect healthcare workers' perceptions of fathers, as Valizadeh et al. (2018) reported in their study, where nurses working in the NICU in Iran perceived fathers as unwilling to participate in their children's care and considered their presence in the workplace as unsettling. Indeed, sociocultural factors play an essential role in determining gender roles and behaviours that may appear modest but are culturally significant (Matsumoto and Hwang 2019). In the present study, fathers' lack of involvement in their children's care and rehabilitation may be attributed to a sense of exclusion stemming from their cultural background. In line with this study, Alabdulaziz (2017) identified cultural and religious norms as barriers to providing family-centred care, in which the involvement of male caregivers within rehabilitation settings in the current study had been perceived to be unacceptable, thus limiting the participation of all family members. Whilst Saudi Arabia's law designates men as the legal guardians and grants them the authority to make decisions regarding the family, cultural norms, such as segregation, conflict with this authority and prevent fathers from actively engaging in the care of their children.

In the Western context, no studies have identified cultural barriers to FCC or father involvement, which suggests that this cultural finding is unique to the Saudi context but may also be found in

other contexts that have not been explored. The cultural differences and norms should therefore be considered in clinical practice within the context of FCC. In fact, Hollins (2018) emphasises the importance of understanding and appreciating different cultures to improve both the quality of clinical care and the quality of interactions with one another. Additionally, it is essential to acknowledge the contradictions imposed by culture regarding the importance of family in a child's life and the extent to which such social contexts influence their involvement and participation in care. This is necessary to overcome these barriers and to promote the importance of family in childcare in Saudi Arabia, a country where such views are prevalent. To increase fathers' awareness and involvement in their children's care, it may be beneficial to educate them about their role in care, thereby advocating for a change in Saudi healthcare policy and regulations that would permit the presence of fathers in a rehabilitation setting.

7.5.3 The Provision of Support

This study heavily focused on the provision of support for families of children with disabilities, as such support was regarded as integral to the meaning and experience of family-centred care. In the rehabilitation context, the extent of support appeared to be limited to emotional and financial support and was restricted by the physiotherapists' limited ability to refer (see section 7.6.1). This finding was considered significant for the development of family-centred services in Saudi Arabia, considering the critical role healthcare professionals play in providing support to parents during their child's first two years of life (Boelsma et al. 2021). When such a role is hindered, as in the present study, it will negatively affect their lived experiences. Indeed, the substantial burden placed on parents caring for children with disabilities, such as the child's expenses associated with medical services, transportation, and school-related costs, hindered their ability to care for their children (Muller-Kluit et al. 2018). For Saudi families, financial resources are considered a significant concern that is necessary to help them properly care for their children (Alkohaiz 2018). Therefore, highlighting the significance of financial support to families and the proper implementation of family-centred care.

The use of spiritual motivation and faith by physiotherapists appeared to provide emotional support; for instance, Adam's strategy was to help parents gain strength, power, and hope by enabling them to become closer to Allah, an approach that was profoundly rooted in his religious beliefs and faith. Whilst Adam used the family's cultural strength as a means of providing support for them, he did not recognise it or perceive it as FCC. However, his approach was consistent with the FCC principles outlined in Chapter 2. These principles emphasise the importance of adapting care to the family's requirements, recognising their cultural diversity, and providing them with support that respects and complies with their values. Such support is valuable, as Terp et al. (2021) demonstrated in their study, how emotional support provided by the medical staff strengthened the relationship and interaction between the team and the parents.

In agreement with previous FCC literature, group therapy and support groups, where mothers interact during their children's sessions, were also identified as valuable sources of support for families in this study. Indeed, Ziegler et al. (2019) believed that such interactions could motivate, support, and relieve the loneliness and isolation experienced by mothers of children with disabilities. They further purported that having the support of the child's therapist has given mothers more confidence about their children's rehabilitation, as they feel reassured and confirmed by the therapist (Ziegler et al. 2019). Within the rehabilitation context, obtaining support from the medical staff could greatly assist parents in gaining an understanding and acceptance of the condition (Arcuri et al. 2015), which is achieved through effective communication (as described in the following).

It appeared from the current study that mothers' experiences with support reflect their ongoing need for guidance and assistance to gain a deeper understanding of their children's condition, thereby alleviating their burden and facilitating the rehabilitation process. In line with previous literature, one of the key aspects of FCC revealed was the constant parental need for support from healthcare workers. Indeed, mothers expressed their constant need for guidance and support, as they lacked the self-confidence to cope with the demanding life circumstances associated with childcare (Poojari et al. 2021). After receiving support from the child's therapist regarding the child's care, mothers felt more competent and confident in undertaking the child's rehabilitation (Ziegler et al. 2019). Myrhaug et al. (2014) found that parents valued receiving

respectful and supportive care, which was closely linked to receiving financial and social support, as well as receiving more child-directed services, contributing to their feeling of respect and support. In more recent research, both Shevell et al. (2018), and McManus et al. (2019), described how parents rated the domain of 'respectful and supportive care' the highest, emphasising the importance of receiving appropriate support services provided in a respectful manner that meet families' unique needs.

Since the provision of support within the context of family-centred care is considered an integral part of meeting the needs and desires of parents (The American Academy of Pediatrics; Policy Statement 2003), therefore, it is important to consider the varying levels of support needs when implementing it within the Saudi context, in a way that aligns with the principles of FCC, the needs of Saudi families, and the cultural context that bounds such provision of support.

Comparing the concept of support for families of children with disabilities in different contexts, it can be seen that support in the Middle Eastern context could be perceived differently than it might be perceived elsewhere or, in this case, in Saudi. In the current study, support meant receiving guidance, help with the child's rehabilitation, and financial assistance. Though both cultures may have similar religious norms and customs, Jordanian parents received support in a different manner. As defined by Saleh and Almasri (2013), support refers to the physiotherapist's efforts to provide coordinated services by providing consistent information to parents and working with at least one family member over a period of time, thus showing a sense of respect and support for the parents. In Western cultures, providing supportive and respectful care, such as receiving financial and social support, was associated with greater parental satisfaction with care, in which parents felt respected and supported (Myrhaug et al. 2014). In addition, it was revealed that the therapist's support gave the mothers the confidence and ability to pursue their child's rehabilitation (Ziegler et al. 2019).

The provision of support is a pivotal aspect of care that aligns with the goals of the 2030 vision, in which members of society are safeguarded by caring families and supported by an empowering social and healthcare system (Vietor and Sheldahl-Thompson 2018). As stated in the vision, families will be offered all the necessary help to care for their children and develop their unique

skills and abilities. Moreover, specialized care and support will be extended to the most vulnerable individuals (Vietor and Sheldahl-Thompson 2018). Furthermore, it aims to strengthen coordination and integration between health and social care, as well as assist families in providing home care for their relatives when necessary (Vietor and Sheldahl-Thompson 2018). Therefore, this vision will seamlessly facilitate the integration of support into the health system, benefitting children with disabilities and their families. By providing coordinated care, the vision guarantees families access to the necessary resources for childcare. It also assures collaborative efforts between health and social care professionals to provide the best possible support for children with disabilities and their families.

Considering the above and the importance of meeting families' individual needs and desires within the context of family-centred care, various forms of support must be provided to ensure a successful approach to child rehabilitation. This support is universally regarded as an integral component of the FCC.

7.6 Similarities

7.6.1 Limited Authority to Refer

Both the physiotherapists and the mothers expressed concern about the limited authority physiotherapists had to refer patients for support. The impact of this has been significant on their ability to provide financial support to families, which in turn affected their ability to fulfil one of the main principles of FCC, which is support. Even though the Saudi Arabian government provides free healthcare to people with disabilities in government health institutions covering rehabilitative, medical, social, psychological, educational, and professional services that assist disabled people in reaching their maximum functional efficiency, and financial support, however, this support remained limited.

It has been found in the present study that the lack of authority was related to the fact that physiotherapists' lacked the autonomy to make decisions, such as directly referring families to the necessary support. This had a negative impact on parents' overall experience with childcare, as they perceived it to be a lengthy, exhausting procedure that added an additional burden to the responsibilities they were already carrying. In previous literature, however, such barriers have not been identified in family-centred care, which might limit its relevance to Saudi clinical settings, where healthcare workers are not very autonomous, unlike healthcare workers in other countries. Indeed, interprofessional duties and autonomy were discussed in Subahi's (2021) study, in which physicians' referral reports to physiotherapists were criticised for being so detailed that they dictated what physiotherapists should do. Such circumstances challenged the autonomy of physiotherapists as they could not modify treatments according to their preferences or even refer patients to receive financial assistance, like in the current study.

The inability to provide adequate support within the rehabilitation context due to these barriers goes against the principles of FCC, which emphasise the need for both formal and informal support for families to ensure their full participation in the care of their children. Consequently, these barriers negatively impact the implementation of FCC in Saudi Arabia, as families' needs and desires might not be fully met. To address this issue, it is crucial for the healthcare community in Saudi Arabia to recognise and work towards resolving the limitations faced by physiotherapists in terms of autonomy and referral authority. By doing so, they will align the provision of care with the values and principles of FCC, ultimately serving the best interests of children with disabilities and their families. This may involve reviewing healthcare policies and regulations, promoting interdisciplinary collaboration, and empowering healthcare professionals, including physiotherapists, to make informed decisions that support the needs of families within the cultural context of Saudi Arabia.

The 2030 vision seeks to improve healthcare systems, making them more efficient and accessible for end users (patients) (Vieter and Sheldahl-Thompson 2018). Consequently, the limited authority to refer may be reformed and will no longer be an obstacle to care. This change will enable healthcare providers to refer patients to appropriate specialists, ensuring that patients receive the best care possible. Additionally, this will also create more efficient systems that help

to reduce wait times, reduce costs, and increase access to care (Vietor and Sheldahl-Thompson 2018).

7.6.2 Communication as the Cornerstone of Family-Centred Care

The development of communication begins in utero and continues throughout childhood and early adulthood (Hutchon et al. 2019). The importance of communication in rehabilitation and the provision of family-centred care was raised by this study, in which effective communication impacted two distinct levels: the communication between physiotherapists and mothers and the communication between the mothers themselves.

❖ *Communication between physiotherapists and mothers*

In this research, communication played a pivotal role in guiding the clinical practice of physiotherapists, aligning services with the children's and families' needs, facilitating treatment, and ultimately improving the children's health and progress. Establishing honest and open communication between families and physiotherapists was considered a valuable strategy for fostering a relationship between them and better understanding the family's situation and needs as a whole. Within the family-centred care context, communication is essential to ensure harmony between the healthcare workers' and parents' desires and plans. This collaborative relationship is deemed fundamental to the ongoing design and evaluation of interventions and care models, as well as the implementation and advancement of FCC (Franck and O'Brien 2019).

Additionally, communication contributed to the parents' understanding and awareness of their child's condition and was regarded as an essential element of the child's rehabilitation and care, as both physiotherapists and mothers described it as a "*must*". In line with Argall et al. (2021), communication played a crucial role in assisting parents in understanding the assessment process, a child's developmental profile, and their future healthcare needs. Moreover,

communication outside of working hours facilitated the continuity of care at home, ensuring that mothers understood the instructions provided by physiotherapists; therefore, making the mothers responsible for leading care at home. Boelsma et al. (2021) demonstrated that clearly communicating what parents can realistically expect from their interactions with child health centres ensures that parents have attainable expectations regarding the support and guidance they will receive.

Previous literature within the FCC context has investigated the value of communication and its significance for mothers (Ziegler et al. 2019). The most recent study by Argall et al. (2021) emphasised the necessity of maintaining open communication between parents and healthcare professionals within the clinical care context, fostering an effective rapport between them. Moreover, parents appreciated having a safe environment where they could express concerns and opinions, obtain answers to their questions, and acquire a comprehensive understanding of the various treatment and service options available (Terwiel et al. 2017). The ability to express concerns and receive candid answers to their questions is crucial in Saudi clinical settings, as highlighted by Alnajjar and Elarousy (2017). Indeed, it was discovered that parents were more likely to engage in their children's healthcare when they could openly and interactively communicate with healthcare providers and receive guidance concerning their child's treatment and care (Vasli and Salsali 2014). The significant impact of communication on parents within the context of family-centred care underscores its importance to them, their children's rehabilitation, and in this study, their lived experiences with FCC.

❖ *Communication between the mothers themselves*

Communication between mothers was considered a vital source of encouragement and support for them and was found to be an essential aspect of their experiences with their child's care and rehabilitation. In Saudi Arabian culture, communicating and socialising with one another is an integral part of daily life, with women tending to be more open and sociable than men, as Adam implied, "*But females are naturally social*" (Lines 149-150). Parents were able to gain assistance

regarding their child's condition through communication, resulting in an enhanced understanding of the child's situation.

The profound impact of communication on the mothers in this study was consistent with previous literature, such as Schreiber et al. (2011), in which such support enabled parents to interact with other parents in similar circumstances, thus forming connections within their communities through formal and informal group programmes (Ridgway et al. 2021). Similarly, Poojari et al. (2021) revealed that many caregivers demonstrated a lack of peer support and a desire to communicate with and learn from other parents, where such was considered helpful in facilitating a sense of belonging and unity in a supportive group which aids parents in developing rapport with one another. Within the context of FCC, family interactions were found to be crucial to the successful implementation of family-centred care (Murrell et al. 2018). This aligns with the cultural context of Saudi Arabia, where Madi et al. (2019) highlighted the significance of support groups for mothers of children with CP, with interactions empowering parents to become fully aware of their children's rights and strengthening their ability to cope with the challenging and demanding roles of raising children with CP.

Moreover, Emam et al. (2021) identified a correlation between parental stress and social support, with participants experiencing high levels of parenting stress receiving less social support. Nazzal and Al-Rawajfah (2017) examined the essential needs of mothers for social support and sharing the burden of caring for children with disabilities, which resulted in women regaining their energy through this support, thereby relieving them of their caregiving responsibilities for a brief time. Although these associations appear meaningful, they were not revealed in the results of the current study. Nevertheless, it is essential to investigate this further and consider the profound effect of support resulting from effective communication when integrating FCC into Saudi rehabilitation settings, given its cultural significance.

Although communication was one of the most important themes reflected in this study, it was often overlooked in research surrounding family-centred care, with only a few studies from the literature, such as Argall et al. (2021), Arnadottir and Egilson (2012), Ziegler et al. (2019), and Poojari et al. (2021) identifying it and revealing it as a desire for parents. This highlights its

significance and importance to parents. Overall, parents described asking questions and expressing concerns as a crucial aspect of communication between them and healthcare workers treating their children, which they highly valued (Argall et al. 2021). Similarly, Ziegler et al. (2019) found that mothers primarily valued communication, which included discussing their concerns and finding answers to questions. In Arnadottir and Egilson (2012), parents expressed a desire for improved communication between their child's school and therapists, leading to the emergence of the theme 'communication and respect'. The results of this study concur with those of previous studies, indicating that mothers seemed to highly value communication. However, this study and earlier studies raised a persistent issue in which mothers desired improved and more coordinated communication between themselves and the healthcare professionals treating their children. For example, Basmah conveyed her desire to communicate more effectively with healthcare providers by stating, *"It is really important for me, and I wish it happens with me a lot."* (Lines 270-271).

This study identifies communication as the overarching theme under which many aspects of care and FCC principles are supported. It serves as the medium through which information is conveyed, roles are negotiated with parents, support is obtained, and rapport is developed between the physiotherapist and the parent. According to Murrell et al. (2018), when families and their children's healthcare providers are unable to communicate effectively, parents experience a higher level of tension. This demonstrates that family-centred care principles, such as communication, are vital not only for a positive experience for families (Murrell et al. 2018), but also for the participants of this study. Indeed, the successful implementation of FCC in clinical settings requires enhancing communication between families and clinicians to foster partnership (Argall et al. 2021). Utilising a communication model, as suggested by Jazieh et al. (2018), could facilitate the family's involvement in patient care in societies with large families, such as in Saudi Arabia. A communication model such as the LEARN model, proposed by Smith and Coleman (2010), can be adopted, which emphasises the importance of clear communication between parents and nurses before negotiating care for an infant to avoid misunderstandings and misinterpretations. Although this model was developed within the nursing profession, it can be transferable to physiotherapy, serving as a tool to guide communication within the rehabilitation

context. By doing so, the family would be able to participate in the patient's care without compromising the patient's autonomy or rights (Jazieh et al. 2018).

Kortleve (2021) suggested that adopting a coaching role during communication is a viable strategy for physiotherapists. For example, by coaching parents, physiotherapists offer essential support to help parents better understand their child's condition and equipping them with strategies to manage the disabilities effectively. Moreover, physiotherapists can also provide advice on how to create realistic goals and strategies for achieving them. Such communication is aimed at fostering a sense of choice and agency in the parents (Kortleve 2021). This approach empowers parents of children with disabilities to make full use of their own personal capabilities and autonomous motivation according to their own needs and desires, which highlights the significance of communication.

The significance of maintaining open channels of communication is supported by the 2030 vision goals, which seek to raise awareness of the significance of communication between children and their families in the education and healthcare sectors (Vietor and Sheldahl-Thompson 2018). This can also lead to better communication and trust between parents and children, which can help nurture a child's development and improve parental involvement in the child's care.

Despite the positive impact communication had on guiding the physiotherapist's practice, establishing rapport with families, assisting mothers in better understanding their child's condition and feeling supported by their peers, this study revealed that some barriers to communication provision still exist within the Saudi context, such as language differences.

7.6.3 Language Difference as a Barrier to Communication and Support

The present study revealed that language differences between physiotherapists and caregivers impeded communication and support during rehabilitation. This included the difficulty and conflict of communicating with healthcare professionals who speak a different language than parents and the problem of comprehending what is being said and requested. The use of the

English language by physiotherapists, especially in front of mothers, was found to hinder communication between the two parties, as mothers perceived the use of English as a deliberate attempt to exclude them from the conversation and from learning information about their children. Mona's experience as a mother illustrated this point, where she felt excluded from the communication process, stating, *"like even sometimes when I sit with the therapists, she talks in English, so she does not explain to you the condition..." (Lines 98-100)*. This exclusion seemed to oppose the principles of family-centred care, which promotes family involvement and participation. Such attitude has hindered the mother's understanding of the child's condition and the rehabilitation process in general, thereby preventing her from actively participating in the child's care.

The presence of language barriers negatively impacted the delivery of healthcare services and patient satisfaction, resulting in miscommunication between healthcare providers and patients (Al Shamsi et al. 2020). In the previous nursing literature, Alabdulaziz (2017) demonstrated that language differences between healthcare workers and parents prevented effective communication and interaction within the context of family-centred care in Saudi Arabia, which aligns with the current study. This may be due to the fact that the physiotherapy community in Saudi Arabia consists of multi-national staff, some of whom speak Arabic, but the majority do not, thereby creating barriers to communication between the staff and parents. Indeed, Saudi Arabia has one of the world's most culturally diverse labour forces, with approximately 63% of the nursing workforce consisting of foreign professionals from various cultural and linguistic backgrounds who provide healthcare to Saudi natives, which creates a barrier to communication (Almutairi et al. 2015). As both studies were conducted in the same cultural setting, this may confirm the conclusion that cultural barriers may inhibit the provision of FCC and its elements, such as communication.

In a different context, barriers caused by language differences have been highlighted in the literature within the context of family-centred care by Arcuri et al. (2015), who concluded that the use of medical jargon during the process of discussing the child's medical condition with the family had also created a communication barrier. As a result, an interpreter was required to act as a communicator between the parents and healthcare workers to facilitate the parents'

understanding of the diagnosis (Arcuri et al. 2015). Although this barrier was identified in the present study, there were no indications that physiotherapists or mothers required the presence of an interpreter, which would have had additional implications on the care provided and on the provision of family-centred care. As Almutairi (2015) indicated, a patient's and a healthcare provider's ability to communicate effectively is influenced by language proficiency. In cases where a provider's language differs from that of their patients, adverse events can occur, and this study found that mothers felt unsatisfied with care and had a negative experience, such as the mother Wed. This indicates that language plays a significant role in various aspects of childcare, such as communication, where differences in language may lead to parents' dissatisfaction and reduced level of involvement and family-centred care.

Consequently, it is essential to address this issue through various methods. The first stage is to raise physiotherapists' awareness of the problem and inform them that it exists. By recognising that communication is a two-way process, physiotherapists can better understand the issue and address it more effectively. Using simple language and layman's terms instead of medical jargon when communicating with parents can also be a solution, as it demonstrates consideration and respect for the cognitive level of parents and ensures that communication is conveyed in a manner appropriate to their level of education and comprehension. Indeed, it is essential that healthcare professionals and parents speak the same language to facilitate effective communication (Almutairi 2015). In addition, it is necessary to create a secure environment for all participants, allowing them to express their concerns and desires and giving them sufficient time to do so.

The 2030 vision brings with it certain challenges as Saudi Arabia seeks to recruit new staff from foreign countries; there will be in-depth necessary training to facilitate them to work within the Kingdom (Vietor and Sheldahl-Thompson 2018). While quality training is guaranteed, potential language barriers may still exist and could pose a significant obstacle to healthcare delivery if not addressed properly. To address this issue, it is imperative that healthcare institutions and centres invest in language and cultural training programs to ensure that staff from a variety of backgrounds are able to communicate with patients effectively. Furthermore, healthcare

institutes should also provide access to language translation services, ensuring no patient feels isolated or misunderstood.

7.6.4 The Impact of Lived Experiences on Perceptions and Understandings of Family-Centred Care

The mothers' and physiotherapists' experiences with childcare and rehabilitation were influenced by cultural factors such as gendered roles and ideologies, family dynamics, family responsibilities, the burden of care, and emotional labour. In addition, cultural influences on parental involvement, difficulty locating information and support, and the need for improved communication all contributed to their perceptions of family-centred care. Indeed, the mothers and physiotherapists who participated in the study exhibited misunderstandings or a lack of comprehension regarding the concept of FCC and its meaning, indicating a sense of unfamiliarity and a lack of knowledge regarding family-centred care. Despite efforts to explain the meaning of the term FCC, they were unable to grasp it as it was challenging to comprehend. Furthermore, the mothers and physiotherapists did not share the same perspectives on family-centred care, as evidenced by their narratives.

❖ *The Mothers*

The mothers did not comprehend the term 'family-centred care', as nearly all of them claimed to have never heard of it. Their immediate responses to the question did not seem to provide answers or reflect their perspective; instead, they appeared to redirect the question to me by saying 'you mean' before answering, as if seeking confirmation of what was being said. Using language such as "you mean", "no", "I think it means", "is that right?" and "I don't get it" demonstrates their hesitancy and lack of understanding of what family-centred care entails. In

fact, the Cambridge Dictionary explains that the use of the phrase "*you mean*" in an answer indicates an element of uncertainty or surprise. This may suggest that the mothers did not perceive themselves to have lived or experienced family-centred care during their children's rehabilitation, as they did not attribute any meaning to it.

The concept of family-centred care was nonetheless defined by the mothers, as described in the cross-case analysis (Chapter 6, see pp. 192 and 193), where it was perceived as a type of service provided by physiotherapists or the centre rather than a method or way of delivering services and rehabilitation. According to the mothers' narratives, different definitions and interpretations of FCC were reflected, including '*home care*', '*family as the primary caregiver*', '*assistance with finding other services*', and '*following a treatment plan at home*', thus confirming their lack of understanding.

This study differs from others (Dickins et al. 2010; Schreiber et al. 2011; and Arcuri et al. 2015) in that the mothers lacked understanding of the concept as a term, whereas participants in previous studies were able to describe and share their perspectives on family-centred care as they had experienced it and attributed meanings to it. As Dickins et al. (2010), Schreiber et al. (2011), and Arcuri et al. (2015) demonstrated, in this context (all studies outside of Saudi Arabia), family-centred care was generally understood and positively perceived by parents. Despite this, it is relevant to emphasise that these studies examined FCC as a service, in contrast to the present study, which investigated the understanding and the meaning attached to FCC as experienced by participants.

Upon further interpretation and analysis, it is possible that the lack of understanding in this study was attributable to the mothers' educational level, as there was evidence that the mothers' sociodemographic characteristics (e.g., academic level) had a significant impact on how they perceived and understood family-centred care. The possibility of an association has been confirmed after reviewing the demographic characteristics of the participants. In fact, two of the four mothers who denied knowing the concept and provided unfamiliar definitions had a lower educational level, less than a bachelor's degree, and no work experience. This is consistent with the findings of Molinaro et al. (2017), who discovered a link between Italian parents' perceptions

of family-centred care and sociodemographic characteristics and marital status, rather than the child's disability. According to other studies in the literature, such as Garant et al. (2002) and Stefansdottir et al. (2015), parents' perceptions of FCC are influenced by the child's disability, level of functioning, and age. However, this was not revealed in the current study. In order to determine whether such associations exist, it is necessary to investigate further the demographic characteristics of the participants. Nonetheless, these correlations should be interpreted with caution due to the possibility that demographic differences may influence their significance.

The lack of understanding could have been an issue in the current study, as I struggled to simplify the term for mothers to ensure their understanding. Despite this, prompt questions were used to elucidate their experiences so that it could be determined whether or not mothers actually received family-centred care for the rehabilitation of their children with disabilities. They were, however, unfamiliar with it, and for mothers and families to accurately reflect on their experiences, it is crucial that they comprehend the meaning of FCC as a concept. As a result, this could serve as a further recommendation to teach families about the principles of FCC, explain what it entails, and then use FCC in rehabilitation settings for a considerable amount of time before conducting further research on the subject, as the educational level influences one's comprehension of such a concept.

❖ *The Physiotherapists*

Whilst the physiotherapists had different definitions of family-centred care, most acknowledged that the family was involved in the child's rehabilitation (See pp. 199 and 200). Primarily, it appeared that the physiotherapists were unfamiliar with the concept of family-centred care, as their responses began with phrases such as, "*Maybe that's what you mean*", "*I heard that*", and "*I perceive that*". This may indicate hesitance in answering the question due to a lack of familiarity with this concept. Indeed, physiotherapists seemed to have interpreted family-centred care according to what they had heard, felt, and assumed, rather than according to their knowledge of the term, suggesting a vague understanding of the concept.

There was, however, a variety of meanings associated with FCC, such as '*group therapy*', '*education of families*', '*support*' of those families, etc. Surprisingly, only one physiotherapist (Hanaa) perceived FCC as an approach that focuses on and acknowledges the family around the child, as she implied in her response (section 6.3.1.1, p.207). Hanaa's attitude towards the family could be explained by her years of experience and work with families, as Hagedoorn et al. (2021) demonstrated that nurses' years of experience affected their opinions on the importance of family, with nurses with fewer years of nursing experience more likely to hold opposing views. Whilst this might be a possible explanation, it may not be as valid as it appears.

After reviewing the demographic information of the current study participants, it was discovered that some physiotherapists had 11 years of experience interacting with families and children, whereas others had 25 years of experience. The wide range of years of experience amongst physiotherapists in this study contradicts the conclusion of Hagedoorn et al. (2021), as there is no correlation between years of experience and therapists' attitudes towards the family. This suggests that within the context of rehabilitation in Saudi Arabia, the perspectives and perceptions of families and their role in rehabilitation were not influenced by the physiotherapists' years of experience. Consequently, this interpretation may not be relevant to the current study and requires further investigation.

However, Hanaa's distinct perspective could be linked to her Indian cultural upbringing, which made her more familiar with family-centred care and family participation in rehabilitation. Feeg et al. (2016) underlined the influence of religious views and backgrounds of healthcare workers on their impressions of working with children and parents. Such differences were believed to challenge the healthcare staff's ability to understand FCC's fundamental philosophy, model, or care system (Feeg et al. 2016). In fact, it has been shown that in studies conducted in Western cultures, including Dickens (2010) in Australia and Arcuri et al. (2015) in Canada, family-centred care was understood and perceived positively by therapists, who had a meaning to FCC, in contrast to the current study.

This may be due to the fact that family-centred care was introduced to those therapists during their undergraduate studies, as opposed to this study, where it may not have been introduced

due to the fact that physiotherapy was introduced late in Saudi Arabia (Alghadir et al. 2015). In fact, physiotherapy is a growing profession in the Kingdom (Al-Eisa et al. 2016), that may not be supported by advanced Western models of health care, such as family-centred care, which are prevalent in Western countries. Therefore, in light of their different cultural backgrounds, the physiotherapists in the present study had differing views regarding working with families.

In addition, Steragaard et al. (2020) identified that in developed countries, nurses appeared to have positive attitudes towards the importance of family in nursing care as they accepted the continuous presence of the family in their patients' lives. This highlights the significant impact of a healthcare worker's cultural background and beliefs on their perceptions and impressions of family involvement and presence during a child's medical care. This may be the case in the current study, where physiotherapists held differing perceptions of working with families and children due to their varying clinical backgrounds and beliefs.

In my role as a physiotherapist, I assumed that healthcare professionals would have a more comprehensive understanding of FCC than mothers, as they often interact with parents during therapy sessions. Many of the children suffering from disabilities in Saudi Arabia's rehabilitation centres also have intellectual disabilities, which make them incapable of communicating or responding independently; thus, parental involvement is crucial for the success of their rehabilitation. However, this study did not support this assumption, suggesting that the physiotherapist's lack of familiarity with the concept of FCC might be due to the absence of exposure to the term family-centred care during their undergraduate studies or work experience.

Reflecting on my experience as a researcher and a physiotherapist who studied and worked in Saudi Arabia, I was not exposed to the concept of FCC during my undergraduate studies in paediatrics; as a result, I was unaware of it. I was first introduced to the FCC whilst pursuing a higher-level degree outside of Saudi Arabia due to the limited number of postgraduate programmes available in the country. This sparked my interest in the subject, thus increasing my knowledge of it.

My reflection on this experience is not any different from those of other physiotherapists, as this was cited by Alodaibi et al. (2022) study, where physiotherapists reported that their

undergraduate education did not cover the topic of health promotion for patients with musculoskeletal conditions. This confirms the observation that different healthcare models or care concepts are not commonly introduced in university education in Saudi Arabia, and consequently, physiotherapists may lack knowledge about them. Given that this may be the case with the physiotherapists in this study, family-centred care must be introduced to them to convey its meaning and emphasise its importance for children's rehabilitation. Additionally, it is crucial that clinical leaders, educators, and managers provide education about the role of active family involvement in patient care in clinical practice and undergraduate education to promote the needed collaboration with families in clinical settings (Østergaard et al. 2020). Incentives to engage parents in health care may convey the underlying message that professionals have confidence in the parent's capacity to care for the child (Salvador et al. 2019), thereby empowering them to become more involved.

Although words such as *'family'*, *'father and siblings'*, and *'support'* were expressed in the quotes of physiotherapists, where they appeared to have more understanding of what family-centred care meant, their interpretations of it differed from what FCC implies, though some elements of FCC were reflected in their clinical practice (discussed earlier). However, the concept of family-centred care did not appear to be well understood by healthcare workers and mothers in Saudi Arabia within a rehabilitation setting. This was supported by prior studies that examined FCC within the Saudi nursing and medical fields, demonstrating that participants had only a superficial understanding of the concept (Alabdulaziz 2017). In spite of this, the mothers and physiotherapists interviewed in this study felt that their current care differed from family-centred care, indicating that their perceptions of FCC were not recognised, but rather they had a perception of FCC absence within the Saudi context of care. Indeed, there was a discussion amongst both physiotherapists and mothers about the perceived absence of family-centred care in the current clinical practice, where they both described the present clinical practice as different from FCC.

7.6.5 Family-Centred Care As 'Different', A Shared Perception of Absence

❖ *The Mothers*

Although the mothers did not clearly understand family-centred care since it had no meaning to them, they appeared confident in that it differed from the rehabilitation services received, in which the physiotherapists focused primarily on the child and not the family. This resulted in the perception that they were not receiving FCC care and made them feel excluded from consideration.

The outcomes of this study contrast with those reported in previous studies (Dickens et al. 2010; Schreiber et al. 2011; and Arcuri et al. 2015), where participants perceived family-centred care primarily in a positive manner. Their understanding of the concept might have been shaped by their actual encounters with it when they were rehabilitating their children, during which the concept had meaning to them; thus, they viewed it positively. In the present study, however, the mothers criticised the actual care they received for not being family-centred as it solely focused on the health of the children, regardless of who brought or accompanied them to therapy. This suggests that mothers perceived FCC as care that extends to those who surround and accompany the child, not just the family.

It was apparent that mothers' experiences of care within the context of the family were not satisfactory and did not meet their expectations, as illustrated by the quotes of mothers Wed and Basmah, as previously mentioned. Mothers appeared to assess the care they were receiving in the context of their own families, as they were unaware of family-centred care and considered it lacking as they did not have meaning to it. In addition to this, it appeared that the mother's reflection on the clinical practice of physiotherapists, as child-centric, contrasts with the definition of family-centred care (Chapter 2), which emphasises the family as a whole, and not just the child, thus recognising all family members as recipients of care.

❖ *The Physiotherapists*

Similar to the mothers, the perceived absence of FCC was reflected in the physiotherapists' narratives, as they described their clinical practice in a way that differed from family-centred care models. Although elements of FCC were evident in their practice, as reflected in the narratives, they perceived their services as being more patient-centred, focusing primarily on the child rather than the family, which is consistent with the mothers' perceptions. Despite this, it was interesting to observe that, unlike the mothers, physiotherapists were able to reflect on their clinical experience with children and expressed concerns regarding the lack of family involvement in physiotherapy rehabilitation. They acknowledged in their responses that limited resources and treatment options were the reasons behind the perceived absence of FCC.

This resonates with previous literature within the context of family-centred care, which has raised the issue of not implementing FCC in clinical practice and the different challenges faced when implementing it. Research, such as that conducted by Dall'Oglio et al. (2018), have shown that FCC was a widely acknowledged concept accepted by healthcare workers; however, its implementation has proven to be ineffective, with participants noting its absence in clinical settings. The poor implementation of FCC was related to numerous factors, including inadequate time and resources, different priorities pursued by hospital clinical governance, lack of competency in the education of families, and difficulty sharing responsibilities with families, as highlighted by Foster et al. (2013). The challenge lay in providing routine nursing care along with the responsibilities of continuously educating and engaging with parents (Mirlashari et al. 2019), a task hindered by the limited amount of time healthcare workers have at their disposal (Arcuri et al. 2015). Due to the overwhelming workload, staff have been unable to fulfil their desire to provide family-centred care in the manner they desired (Arcuri et al. 2015). This is consistent with the findings of Manzuma et al.'s (2021) study, which highlighted how the work environment in hospitals in Kano could be chaotic, leaving physiotherapists with insufficient time to be reflective and sensitive to the needs of families. Within the context of rehabilitation in Saudi Arabia, physiotherapists face similar challenges and constraints, which might affect their willingness to provide family-centred care to children with disabilities, as one physiotherapist explained.

From the above, it can be inferred that different healthcare workers, including physiotherapists, face persistent challenges when providing family-centred care, primarily due to limited time, limited resources, and heavy workloads. The persistence of this issue requires assessment and identification of solutions, such as providing longer treatment sessions to allow for the full engagement of parents, decreasing the workload on physiotherapists, and assigning a gatekeeper responsible for some of the roles a physiotherapist has to fulfil. In general, the participants were unable to recognise FCC as a concept due to a lack of understanding and, therefore, perceived that they were not experiencing it. This is likely due to both physiotherapists and mothers being unaware of the FCC concept, as it is a Western model of care. Nevertheless, it appears that some FCC principles are incorporated into the clinical practice of physiotherapists, but the concept is not recognised in the Saudi rehabilitation setting. This finding sheds light on the current state of knowledge in the research field concerning FCC. It also highlights the conflicting perceptions between physiotherapists and mothers, which has a profound effect on parental involvement and, consequently, on the potential provision of FCC in Saudi.

Cultural influences were evident throughout the discussion, as they impacted various aspects of FCC identified in this study, such as care roles, family dynamics, care burden, family involvement, communication, and support. Consequently, all participants were unable to recognise FCC as a concept or identify the FCC practices employed by physiotherapists in this study. This supports the notion that FCC is more of an inherent concept rather than a well-defined model of care. Gaining a clear understanding of FCC's position as a theory in Saudi Arabia will aid in facilitating its implementation within this context and culture.

7.7 Contradictory Experiences

This section highlights the contradictory experiences of the mothers and the physiotherapists in relation to the mothers' involvement in their children's rehabilitation, as well as the level of that

involvement, and the various forms of involvement that the mothers desired for both themselves and their children.

7.7.1 Mothers' Involvement

Although cultural influences and the attitude of healthcare workers imposed an additional burden on the mothers to care for their children, nonetheless, their presence in child therapy remained significant. In this study, physiotherapists felt that the mother's presence was a 'need' that they sought to fulfil to ensure that the mother comprehends and understands all of the exercises she is required to perform for her child, as Rasha indicated *"So I need to focus on her in the first time she stays with me.."* (Line 118). This sense of proximity and obligation towards the mother reflects the physiotherapists' desire to involve her in the care, ensuring continuity of care and compliance at home. This parental involvement aligns with a family-centred approach, viewed as an empowering tool for parents with limited caregiving abilities, enabling them to comply and continue providing care at home (Sarin and Maria 2019). However, despite the physiotherapist's espousing involvement, mothers appeared to feel excluded, as they perceived that no explicit effort was made to involve them or consider them.

The physiotherapists' espoused desire to involve mothers may have stemmed from their practices guided by Saudi codes of conduct based on 'Sharia'. Sharia refers to the overall Islamic system of ethical, religious, and legal regulations on human life that define Islamic values and laws (SCFHS 2019). These codes of ethics recognise the family's imperative role in the decision-making process and promote a healthcare facility that respects Islamic culture and norms, as well as the physical, emotional, and social needs and well-being of families and patients (SCFHS 2019). However, these practices were not perceived as being involved. This suggests that some concepts of FCC, such as parental involvement, are naturally embedded within physiotherapists' clinical practice rather than formally recognised as a concept.

In light of the conflicting viewpoints, it is possible that the physiotherapists' desire to involve mothers was solely for clinical purposes, such as ensuring compliance with home exercise

regimes. In contrast, mothers' desire to be involved was primarily motivated by understanding their child's rehabilitation, knowing their child's future outlook, and being asked for their desires and wishes. This mismatch exists between what the physiotherapists perceive healthcare to be and what mothers perceive it as being as mothers are involved in care, whilst they feel excluded. Thus, this suggests that mothers require a different level of involvement than provided, which could potentially improve their satisfaction with care and the effectiveness of the therapy. To overcome such dichotomy, it is crucial to negotiate roles, expectations and wishes through communication between therapists and families, ensuring a better care.

This study provides a unique contribution to current knowledge by highlighting conflicting views on family-centred care (FCC) that have not been previously reported. This may be attributed to the fact that prior studies have used diverse methodologies, including quantitative and qualitative approaches as well as mixed methods, to evaluate parental perceptions of the family-centredness of services. In contrast, this study employed interpretative phenomenological analysis, a more detailed methodology used to explore the lived experiences of participants regarding FCC, leading to a different outcome. Another possible explanation for the novel findings of this study is that FCC is not widely recognised as a model of care in Saudi Arabia, where this study was conducted.

Nevertheless, the differences in perceptions between mothers and physiotherapists can be explained by their varying expectations, desires, and levels of involvement, which were not disclosed before the child's rehabilitation. The findings reveal that physiotherapists involved mothers in their children's rehabilitation process but may have neglected to involve them in other aspects of care that mothers considered more crucial to their involvement, as discussed earlier. There was a wide range of parental involvement desired by participants were some mothers preferred to be actively engaged in their child's treatment, whereas others relied on physiotherapists to carry out the exercises. Indeed, the narratives of the mothers in this study reflected two themes: 'physiotherapy as hope' and 'therapists as the experts' (p.189), in which some mothers regarded physiotherapy as their only hope and relied on it because of its perceived impact on their lives.

Several factors might have influenced the level of mother involvement in the rehabilitation and care of their children, as revealed by this study. Amongst these was the mothers' lack of knowledge and expertise in childcare due to their perception of themselves as having insufficient skills to care for their children at home. This self-perception might have been influenced by the cultural context in which they live, where giving birth to a child with a disability is perceived as a failure in motherhood (Alariefy 2016). Consequently, these social views have contributed to their hesitation to take on full responsibility for their children with disabilities, negatively impacting their self-image.

In addition, feeling inferior to healthcare providers was also considered one of the possible factors that influenced parental involvement in childcare. Indeed, parental views of healthcare workers to know better were previously discussed in nursing literature, such as the study (Neu et al. 2019). Parents preferred to leave complex caring tasks to nurses, and in some cases, mothers were hesitant to make their own choices and decisions because they saw nurses as in charge of directing and caring for their infants in the ICU (Neu et al. 2019). Parents appeared to delegate decision-making responsibility to hospital staff, indicating they did not consider themselves competent to care for or make decisions regarding their critically ill child (Mirlashari et al. 2019). While it could be argued that an intensive care unit is a different setting than a rehabilitation facility or at-home physiotherapy, parents in different settings shared a similar perception of how healthcare workers were experts in child care.

Indeed, in the context of family-centred care in rehabilitation, parents in Poojari et al.'s (2021) study relied on healthcare providers to make decisions about their children's care and felt that this was their responsibility. Parents' respect for healthcare professionals stemmed from their conviction that they would provide the highest quality of care for their children, as Poojari et al. (2021) concluded. The present study's findings and the study of Poojari et al. (2021) demonstrate the prevalence of these perceptions among parents in various clinical settings and cultural contexts; in Saudi and India. Nonetheless, holding these beliefs makes it more difficult for the caregivers to comprehend their role and the importance of collaborating with the

professionals (Poojari et al. 2021), which can have a negative impact on parental involvement in the care of their children.

On the other hand, there were some parents who felt that they were the real experts of their children. Mother Salma, for example, explained how she tried to learn physiotherapy techniques from different sources to provide her daughter with the most effective care possible, which she believed to be the most appropriate treatment for her daughter. This belief seemed to illustrate the extent to which Salma considered herself to know her child better than the physiotherapist; and also provided the basis for her desire to be involved in all aspects of child's care. This perception is consistent with previous literature, which suggests that parents, by virtue of their role, are or can be the '*experts*' of their children as they understand them and care for them on a daily basis at home (Byczkowski et al. 2015). Thus, within the context of family-centred care, it is crucial to consider the family's value system and context when considering the child's care (Hill et al. 2017). Furthermore, families should be considered an essential part of a child's life, acting as experts throughout the child's diagnosis, treatment, and decision-making process (Murrell et al. 2018). In Saudi Arabia, where this study was conducted, family relationships are highly valued and considered crucial (Al-Saif 1991).

Despite the importance of family in a child's life, a possible factor that hindered parental involvement, even if they felt empowered to do so, was the power relationship between healthcare providers and parents. Power imbalance has been identified in many studies as negatively impacting parents' self-confidence and their level of involvement in their child's medical care. For instance, Boland et al. (2019) reported that power imbalances in paediatric settings hindered shared decision-making, as children and parents found it difficult to negotiate decision-making involvement and needed support and encouragement from their healthcare practitioners. This may have a negative effect on the implementation of FCC, as suggested by Mirlashari et al. (2019). Clearly, power imbalances affect clinical practice and the provision of services. In this study, such imbalances impacted mothers' participation in rehabilitation and care, as they viewed themselves as inferior to healthcare workers rather than equal, impeding possible partnerships and FCC.

Despite these influences, the above discussion nonetheless reflects the variety of parental needs and desires for involvement in their child's care that was revealed in this study, which was also identified in previous literature regarding family-centred care in rehabilitation. For example, it has been shown in some studies (Arnadottir and Egilson 2012 and Molinaro et al. 2017) that parents value having a consistent therapist responsible for their child's care to foster a closer relationship between therapists and parents. In addition, other studies (Morgan and Tan 2010, Terwiel et al. 2017, and Argall et al. 2021) have demonstrated a parental desire to have a safe space to communicate and express their concerns, while studies such as Argall et al. (2021), Stefansdottir et al. (2015), and Ziegler et al. (2019) have also demonstrated the parents desire to be felt, cared for, and supported.

These studies suggest that different parents with children with disabilities may have varying needs or requests for their children and diverse desires or requirements which they value. An example of this was illustrated by Murrell et al. (2018), who discovered that family culture had a significant influence on the way the diagnosis was desired to be communicated, with varying preferences concerning how the diagnosis was delivered between families, cultures, and educational levels. Indeed, Murrell et al.'s (2018) concluded that families have a wide range of needs across the child's lifespan and various strategies their providers, communities, and support systems have employed to help them meet those needs.

The levels of parental involvement desired by mothers in this study were found to vary and were influenced by the mother's self-perception, as well as her perceptions of physiotherapy and rehabilitation, which were further shaped by the social context in which she lived. These cultural contexts have also resulted in power imbalances that have hindered the involvement of mothers. Consequently, a practice continuum, as advocated by Smith et al. (2010) in their work on family-centred care (FCC) (Chapter 2, p.23), may be necessary. Such a practice continuum enables parents and nurses to determine their desired level of involvement in care, rather than following a hierarchy that leads to parent-led care as the ultimate goal. Nurses can thereby respond to the individual needs of a child and their families as their circumstances change during their care (Smith and Coleman 2010).

It may be possible to adapt a practice continuum for Saudi Arabia, given that it is a different care context and cultural context where physiotherapy is still developing. Western concepts of care, such as FCC, may not be readily applicable in the evolving Saudi context, where cultural influences result in power differences and social expectations. Indeed, in the present study, equal partnership with families, as illustrated by the definition of family-centred care espoused by Canchild (see p.21), is not feasible in Saudi due to power imbalances caused by cultural influences, making it challenging for physiotherapists to work collaboratively with families. Nonetheless, a practice continuum, such as the one developed by Smith and Coleman (2010), could be useful in setting guidelines for establishing a model of care that is relevant to the Saudi Arabian context, in which both parents and physiotherapists have the flexibility to determine their desired level of involvement.

Watts et al. (2014) concluded that it is necessary to assess parents' readiness for involvement in the child's care as part of their engagement process as caregivers. However, in the present study, mothers were not asked whether they were willing to participate in their child's care, despite family involvement being a key principle of FCC. This step is crucial in successfully implementing FCC, and both mothers and physiotherapists must be aware of parents' desires regarding their involvement in their children's rehabilitation and care. Additionally, organisations, practitioners, and families must demonstrate flexibility in their planning and response to diverse needs and circumstances, encourage involvement in decision-making, ensure that inclusive approaches are implemented, and acknowledge the expertise of both healthcare professionals and parents (Ridgway et al. 2021). Therefore, it is essential to determine what parents desire in terms of their involvement in their children's rehabilitation and care to enable the successful implementation of FCC within the Saudi context, which allows parents to actively participate in their children's rehabilitation.

Encouraging and supporting the participation of families in care and decision-making to the extent they desire is crucial, as indicated by the Institute of Patient and Family-Centred Care (Johnson and Abraham 2012). Recognising parents' preferences regarding their involvement in their child's care can also facilitate the prevention of participation in situations that are perceived as beyond their abilities and provide opportunities for successful experiences, thereby increasing

parents' self-efficacy (Salvador et al. 2019). This involves negotiating roles in line with Saudi family dynamics, cultural expectations, and desired outcomes between healthcare providers and parents. Ideally, this negotiation could occur in a group session between family members and healthcare professionals to discuss care issues in-depth before the rehabilitation process. When engaging parents in the care partnership, it is imperative that cultural considerations be taken into account.

Aspects such as the cultural concept of 'family', which may extend beyond that of the nuclear family, the way in which decisions are made regarding the child, and the individuals in the family who are responsible for making those decisions should all be considered (Watts et al. 2014; Purpura et al. 2021). Additionally, adjusting practices to the specific needs and strengths of the child and family are considered fundamental principles of family-centred care (Kuo et al. 2012). This collaborative partnership with parents is believed to be crucial for the ongoing design and evaluation of interventions and care models and, ultimately, when implementing and advancing such models of care such as FCC (Franck and O'Brien 2019).

It can be inferred from the above that where family-centred care is currently situated within the context of this study, using the practice continuum of Smith and Coleman (2010) as a reference, is at the second stage of care, where the nurses lead care with parental involvement. As indicated in the physiotherapist's and mother's accounts themselves, physiotherapy care in this study is led by the physiotherapist, and mothers were involved as well; there was, however, no indication of actual participation in the clinical setting. However, the child's rehabilitation at home is undertaken by the mother, led by the physiotherapist's instructions and guidelines. This confirms the hypothesis that the way in which FCC is currently positioned and developed in Saudi Arabia is quite different from how it is positioned and developed in other countries, such as the United Kingdom.

Considering the burden of care, the different feelings and perceptions that mothers of children with disabilities in Saudi Arabia have, and the cultural influences that prevent mothers and physiotherapists from fulfilling their desires and wishes, it is essential to convey and discuss such influences between the family and healthcare team by providing communication channels that

facilitate such desires, concerns, and worries. In fact, the study's findings indicated that communication is of the utmost importance, as it binds these interrelated elements together in a manner that ensures harmony and coordination between healthcare workers and families.

7.8 CONCLUSION

This chapter has discussed the meanings of both mothers' and physiotherapists' experiences with FCC, comparing the similarities and contradictions arising from these experiences in relation to the broader literature on family-centred care. While FCC was not explicitly recognized by participants in the study, many of its principles were embedded within the country's cultural values and codes of conduct and were reflected in the physiotherapist's practices. Indeed, participants in the study experienced FCC to some extent but were unaware due to a lack of understanding.

Unlike other studies, the cultural context of Saudi Arabia significantly influenced FCC experiences and provisions as well as every aspect of childcare and rehabilitation. For instance, the parental caring roles at home and in the clinical setting, where societal norms around gender segregation restricted fathers from entering the rehabilitation setting and actively engaging in the child's care. This unique positioning intensified the emotional burden on Saudi mothers, evident in the recurring theme of the burden of care. This burden was heightened by cultural expectations that held mothers responsible for their children's health and illness, thus amplifying the feelings of guilt, fear and loneliness of mothers with a child with a disability. Contradictions related to the extent and type of mother's involvement in child's care has emerged from the findings, where mothers and physiotherapists had contradictory experience, all of which has contributed to the understanding of the family-centred approach in the Saudi Arabian context.

Consistent with previous research, this study placed a strong emphasis on the value of upholding family members' preferences and preserving communication, where communication was seen

as the foundation of FCC that ensures the provision of adequate information, support, collaboration, and building rapport between the physiotherapists, children, and families.

CHAPTER 8 – CONCLUSION

Overview

This chapter highlights the significant aspects resulting from the thesis' completion. It starts with a review of the study's rationale and a summary of the main research findings in relation to the study's aims and objectives. This is followed by the implications for clinical practice, in which are evaluated in relation to the three levels of healthcare (Micro, Meso, and Macro). The clinical contribution of the study, along with the study's limitations and recommendations for future research, will be discussed.

8.1 The Study

This study sheds light on a concept of care that has not been well understood in Saudi Arabia. Despite the fact that some of its elements might be inherently embedded in the practice of physiotherapists, however, it is not explicitly recognised. By recognising and understanding this concept, its components, facilitators, and barriers, we will be able to fully benefit from it in a manner that serves the child's and family's best interests.

The provision of family-centred care is essential for the effective rehabilitation of children with physical disabilities because it promotes the well-being of the child and their family within a family-professional partnership that recognises the cultural and individual characteristics of the family. Caring for a child with special needs can present numerous emotional, physical and financial challenges for parents and other family members. Understanding parents' perspectives on the facilities available to their children will enable healthcare services to better meet the family's and child's needs, thereby helping to alleviate parental stress.

Family-centred care has been intensively researched in other countries, yet it remains undefined in the context of Saudi Arabia. Despite its importance in clinical practice, the literature indicates limited knowledge on the lived experiences and perceptions of mothers and physiotherapists specifically in Saudi Arabia regarding FCC for the rehabilitation of children with physical disabilities. Therefore, this study explored the lived experiences of mothers and physiotherapists in Saudi Arabia regarding family-centred care for the rehabilitation of children with disabilities. Four mothers and four physiotherapists from four distinct rehabilitation settings participated in this study.

8.2 Summary of Main Findings

The idiographic and cross-case analysis results revealed five overarching themes in the participants' experiences. These included 'the current status of family-centred care within Saudi Arabia' 'roles of care and family dynamics in Saudi', 'communication as the cornerstone to family-centred care', 'the provision of support', and 'culture as a barrier to father's involvement'. All of these themes have been found to be interconnected to the provision of family-centred care within the Saudi rehabilitative context.

Additionally, the current study revealed that neither mothers nor physiotherapists regard themselves to be receiving FCC because they perceive the existing care to be more child-centred than family-centred. Nevertheless, the results indicate that certain FCC principles were ingrained and evident in the clinical practice of physiotherapists but were not explicitly identified under a particular definition. It could be argued that some of the findings of the current study have not previously been identified in prior research, such as the impact of culture on FCC, because the current study was conducted to investigate and comprehend the significance of participants' experiences with FCC regarding rehabilitation services rather than to evaluate them. Linking the findings to the research question, it is evident that mothers do not possess an FCC approach and instead experience a care burden and negative emotions which lead them to

assume the role of primary caregivers. This was confirmed by the physiotherapists' experiences, which indicated that current care is more child-centred rather than family-centred. Family-centred care as a concept was not understood, as participants had no meaning to it; nonetheless, some of the principles of FCC were reflected in these experiences. This indicates that FCC principles are embedded in practice but not formally acknowledged. Given these factors, applying FCC might be challenging in Saudi Arabia where cultural idioms of roles of care place significant pressure on mothers and increase their burden of care which, in turn, can make them feel burnt out and despondent.

It can be concluded that Saudi culture influences every aspect of Saudis' lives. Indeed, it has affected the participants' experiences of family-centred care and the provision of FCC in this context. This includes segregation in hospitals, forcing fathers to be excluded from childcare, and creating a dichotomy between what healthcare providers want to achieve and what can be achieved in terms of FCC and parental involvement in the rehabilitation and care of the child. However, things are changing in Saudi Arabia as a result of the Vision, with women being empowered and given equal opportunity to work. This may affect their caregiving roles in future and the country is becoming more liberal and open, with a focus on integrating both sexes and reducing gendered segregation (Vietor and Sheldahl-Thompson 2018). However, culture continues to exert considerable influence on Saudi society. As a result, there is a need for the FCC model which respects the changing culture in Saudi Arabia and aligns with the current status of this model of care (FCC) in the Saudi context where physiotherapists typically provide care with minimal family involvement.

Saudi society is characterised by conservative, traditional, and family-oriented values based on Islamic religious instruction. Consequently, parents are liable for the care of their children until they are married or financially secure and once their parents become elderly, it is common for their children to care for them (Alwhaibi et al. 2018). Therefore, the interdependent nature of the culture and the closeness of familial ties that characterise Saudi culture can serve as a basis for implementing family-centred care, despite the fact that it is a Western concept which has typically been applied in more independent cultures. This will allow the concept to be effectively

adopted into Saudi culture and improved upon to reflect the Saudi context, given that it shares the principles of FCC whereby the family is at the centre of all aspects of childcare.

Further consideration should be given to the ideologies of gendered roles, the burden of care imposed by society and the healthcare team, the power dynamics within the healthcare setting (which can make maintaining an equal partnership difficult), the ability of mothers to voice their concerns and desires freely, and the ability of fathers to become involved in the care of their children. Consequently, such a culture requires a modified model of FCC which takes into account the cultural values, norms and customs of Saudi society while promoting care that respects the needs of families of children with disabilities and, at the same time, permitting the amplification of mothers' voices by empowering them, as well as involving fathers in their child's rehabilitation. According to Watts et al. (2014), cultural considerations are essential to involve parents in the care partnership and provide FCC. With a thorough understanding of the factors influencing role distribution, it is possible to implement a family-centre care approach that is compatible with these cultural norms.

Although the concept of FCC has been well-developed globally in the medical literature and legislation (Smith et al. 2015), FCC is still developing in Saudi Arabia in other medical disciplines and there is scope for further expansion in the context of rehabilitation. According to Bamm and Rosenbaum (2007), a paradigm shift can take years or even decades to be thoroughly accepted and implemented in a field. Indeed, evolution is a dynamic process of development and growth during which a theory undergoes modifications and adaptations, is influenced by cultural and political factors, and interacts with other philosophical systems in its field (Bamm and Rosenbaum 2007).

Adaptations must be made according to Saudi cultural values, reflected in the themes that emerged from this study, such as 'communication as the cornerstone to family-centred care', and 'the provision of support', to successfully implement FCC within the Saudi rehabilitation context. These values include the significance of communication, feeling supported and considered, meeting and acknowledging the needs of each family member and respecting the desired level of participation in care. The current study has laid the groundwork for future research on FCC in

a Saudi Arabian rehabilitation setting to help physiotherapists implement this theoretical practice philosophy in the rehabilitation setting and offer services that satisfy the requirements of children and their families.

It is essential to note that although the findings are significant because they establish the foundation for FCC in the Saudi rehabilitation context, there are limitations associated with the study which are discussed below, along with the clinical implications and recommendations.

8.3 Clinical Implications

Healthcare systems consist of three interconnected levels: a microsystem (the patient), a mesosystem (healthcare providers), and a macro system (health policy and/or regulatory procedures) (Sawatzky et al. 2021). According to the study's findings, culture played a significant role at all three levels, including participants' experiences, how services were implemented or structured, and how stakeholders, rehabilitation centres, and physiotherapists provided services. Based on the findings of this thesis, it can be concluded that the three levels of care are essential for implementing family-centred care in the Saudi context.

- *The Micro Level*

The experiences of mothers and physiotherapists are crucial for understanding their personal perspectives on the care and rehabilitation of children within the context of Saudi Arabia. The information obtained from the participants in this study has highlighted their experiences, which can be used to guide the meso and macro levels of healthcare systems.

The burden of care that mothers encountered with relation to their child's rehabilitation, imposed by a variety of contextual variables, has led mothers to feel burnout and perceive the

care provided as not FCC. Mothers were compelled to continue their responsibilities as mothers of children with disabilities but felt that these tasks added to their burden and made them dissatisfied with their child's care and the overall rehabilitation experience. In addition, Mothers expressed a need for continuous support from family members and physiotherapists, a desire to be treated with dignity and equity, and a desire to have their concerns, desires, and wishes addressed.

In their practice, physiotherapists perceived the mother as the child's primary caregiver, imposing an additional burden and expectation on them. As a result, the mother's ability to perform caregiving duties and comprehend the child's condition and disability-related challenges was impaired. This has led mothers to avoid participation and involvement in childcare, relying significantly on physiotherapists for assistance with child rehabilitation.

Based on the study findings, it is possible to conclude that there is an opportunity to educate physiotherapists and raise their knowledge about the burden of care that mothers face, as well as raise mothers' awareness of their rights to amplify their voices and wants within this culture. This will allow moms to voice their desires and needs regarding their child's care and rehabilitation, allowing them to make educated decisions about their child's health and their participation in rehabilitative care.

- *The Meso Level*

The experiences of mothers of disabled children and physiotherapists treating these children have provided an overview of how hospitals offer rehabilitation care for children with disabilities. Healthcare professionals can utilise this information as a guide for designing and prioritising care that meets the needs and requirements of mothers.

Educating physiotherapists and raising awareness about the significance of family involvement in a child's rehabilitation can facilitate change advocacy. In Saudi Arabia, where culture plays a significant role in how care is developed in rehabilitation, additional effort should be expended

to advocate for a change in the healthcare system's legislation (Macro level), considering the country's cultural norms and practices.

- *The Macro Level*

In this study, mothers have identified various shortcomings in the current healthcare system. This included the difficulty of obtaining financial assistance and the need for assistive devices for children. In addition, the therapists' inability to directly refer parents was a significant issue that had a substantial impact on the delivery of services and, consequently, the development and rehabilitation of children. The long waiting times for treatment and the inaccessibility of centres were limitations to the child's rehabilitation.

The issues have prevented mothers from receiving assistance when necessary. This is surprising given that the Saudi healthcare system has undergone significant development and improvement over the past few years. The current system in Saudi Arabia necessitates that physicians refer patients to physiotherapy, a step that could prevent patients from receiving timely support. However, additional system modifications are required to overcome this limitation. It is recommended that the Saudi Arabian healthcare system make physiotherapists the first point of contact with patients. This would assist families in receiving support as soon as possible.

The following are some of the clinical implications of this study:

- 1) To the best of my knowledge, this is the first study in Saudi Arabia which explored family-centred care within the rehabilitation context in Saudi. Therefore, the results provide a guideline for policymakers, which could be helpful in developing policies supporting the provision of family-centred for Saudi children with disabilities and their families that fit the Saudi context.
- 2) The current study contributed to a greater understanding of the concept of family-centred care among study participants, including mothers and physiotherapists. This, in

turn, will assist in raising awareness of FCC for pediatric care among the general public as well as among healthcare staff, allowing it to be implemented appropriately.

- 3) It was found that Saudi culture, family dynamics, and gendered roles are highly influential in shaping the experiences of mothers and physiotherapists with family-centred care and child rehabilitation. This can greatly influence how family-centred care is provided within the Saudi context, where social values, norms, and customs should be respected when adopting such an approach to care.
- 4) This study allowed mothers and physiotherapist to share their stories and reflect on their experiences with child rehabilitation and family-centred care, revealing the influence of culture on women's experiences.
- 5) It has been demonstrated that the current healthcare system does not entirely meet the expectations and rehabilitation needs of mothers and physiotherapists for the care of children with disabilities, as it hinders the provision of care models such as the FCC. Therefore, this research should inform the development of a healthcare system that is culturally sensitive, and that addresses the limitations identified by study participants.

8.4 Study limitations

- 1) One of the drawbacks to this study is being a new researcher. Because of my lack of expertise, I may have missed topics that came up during interviews that needed more investigation.
- 2) There is limited research on family-centred care and the experiences of parents and healthcare workers in Saudi Arabia and other middle eastern countries. This has caused difficulties in locating relevant research that could be used to support and justify the need for the current study.
- 3) The purpose of this study was to explore the experiences of physiotherapists and mothers concerning family-centred care through eight participants. This study is not intended to

provide generalisable findings; however, it does examine patterns across cases and presents some shared experiences that may be relevant to others.

- 4) In an IPA study, participants typically come from a homogenous group; however, the decision to include both mothers and physiotherapists was made to understand better the phenomenon under study, Family-centred care, from both perspectives.
- 5) As data were collected from one area in Saudi Arabia, it may not reflect of the experiences of individuals in other regions. Consequently, it would be intriguing to examine other regions in the kingdom to determine if experiences are comparable or if there are social and cultural differences between regions.
- 6) In keeping with the IPA method, this thesis presents my interpretation of the meaning-making of my participants' experiences; other researchers may have interpreted the data differently.

In light of previous discussions, it is believed that FCC can be facilitated differently within the Saudi context through utilising the interdependent nature of Saudi culture, as well as the strong familial bonds that are embedded within society, in order to promote and increase the awareness and understanding of family-centred care among physiotherapists, parents, families, and the general public. Since culture is considered to play a significant role in how services are implemented or structured, as well as influencing the legislation system and setting rules and regulations by stakeholders as well as rehabilitation centres and physiotherapists. This study contributes to new knowledge in practice as it provides an understanding of the experience of family-centred care. Based on the findings of this study, recommendations can be adopted by physiotherapists, healthcare professionals, and the Saudi healthcare system, with the aim of meeting the needs of children with disabilities and their families.

8.5 Recommendations

- 1) As physiotherapists play a vital role in the management and rehabilitation of children with disabilities, it is crucial to assess their willingness and ability to work with families in an equal partnership that supports FCC principles. This can be accomplished through an exploratory study of physiotherapists working with children to determine their perceptions of the topic and to investigate the cultural barriers they may encounter when working with families in an effort to overcome these barriers and promote a FCC that meets the needs of the child, the family, and the healthcare workers.
- 2) The findings of this study may also be beneficial for physiotherapy training institutions in Saudi Arabia (such as universities and rehabilitation centres) as well as other healthcare institutions, where a greater emphasis would be placed on materials that facilitate the provision of family-centred care for children with physical disabilities.
- 3) The results of the current study show that some parents prefer a more directive approach from their child's physiotherapist, while others desire a shared decision-making process and wish to be more involved in their child's care. Thus, the physiotherapist must assess the preferred roles and forms of care so that they can provide care tailored to the needs of both the child and the parent.
- 4) The dichotomies and contradictions between the experiences of mothers and physiotherapists observed in this study highlight the discrepancies between what is perceived to be done and what is actually done in a child's rehabilitation. This emphasises the importance of maintaining good communication channels between both parties to discuss such contradictions, expectations, needs, and requirements in a manner that is satisfactory to everyone caring for the child. This can be accomplished by utilising communication models or examining parental and healthcare worker perceptions and opinions on rapport building and communication between them.
- 5) In this study, mothers were burdened by the care of their children and the responsibilities they faced as mothers who belong to a culture that places high expectations on them. Therefore, to reduce maternal stress and the burden of care, it is necessary to increase

men's/fathers' involvement and participation in communal roles at home and in rehabilitation centres. Consequently thus improving father's parental role in child's care.

- 6) An effort should be made to develop an educational programme which aims to improve father's self-confidence and efficacy in caring for their families, encouraging their involvement in childcare and stimulating equal divisions of domestic responsibilities.
- 7) In the societal context, the promotion of broader socialisation of gender norms may provide future generations of boys with greater freedom to explore their agentic and communal interests, thus, their caring roles, which will have an impact on FCC provision.
- 8) Although the current study sought to explore the lived experiences of both mothers and fathers, this was not achieved as all the willing participants were females (mothers). Therefore, these results reflect their experiences only. Given that fathers might have different experiences than their mothers, it is imperative to explore their lived experiences to understand family-centred care within the Saudi context better.

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APPENDICES

Appendix A: Ethical approval from Cardiff university

School of Healthcare Sciences
Head of School and Dean Professor David Whittaker

Ysgol Gwyddorau Gofal Iechyd
Pennaeth yr Ysgol a Deon Yr Athrawes David Whittaker



15 August 2019

Cardiff University

T
Email E-bost

Abeer Jamal
Cardiff University
School of Healthcare Sciences

Dear Abeer

The Physical Therapists' and Parents Lived Experiences of Family-Centred Care for Children with Physical Disabilities in Saudi Arabia: A Qualitative Phenomenological Approach

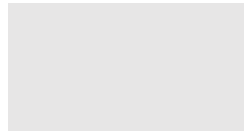
The School's Research Ethics Committee Chair has considered your re-submitted research proposal. The decision of the Committee Chair is that your work should:

Pass –and that you proceed with your Research in collaboration with your supervisor

Please note that if there are any subsequent major amendments to the project made following this approval you will be required to submit a revised proposal form. You are advised to contact me if this situation arises. In addition, in line with the University requirements, the project will be monitored on an annual basis by the Committee and an annual monitoring form will be despatched to you in approximately 11 months' time. If the project is completed before this time you should contact me to obtain a form for completion.

Please do not hesitate to contact me if you have any questions.

Yours sincerely



Research Administration Manager

Cc : Sue Barker & Amie Hodges

Appendix B: Ethical approval from the Saudi Ministry of Health



Kingdom of Saudi Arabia

الموضوع: تسهيل مهمة باحث

الإدارة: إدارة البحوث والدراسات

المحترمين ،،،،،

السلام عليكم ورحمة الله وبركاته...

نفيدكم بأن الباحثين المذكور اسمائهم أدناه سوف يقومون بإجراء البحث وجمع البيانات اللازمة لذلك

عبير سمير جمال ،	اسماء الباحثين
The Physical Therapists' and Parents experiences, views, and perceptions of Family-centred Care for children with physical disabilities in Saudi Arabia: A Qualitative Approach	عنوان البحث
عبير سمير جمال	اسماء جامعي البيانات
سنة واحدة فقط	مدة البحث
١٠٥٧ .	رقم البحث

وبعد الاطلاع ودراسة منهجية البحث من قبل اللجنة العلمية ولجنة أخلاقيات البحث العلمي المسجلة لدى اللجنة الوطنية للأخلاقيات الحيوية والطبية برقم (H-02-J-002) وجد أنه لا مانع من إجراء البحث.

لذا نأمل تسهيل مهمة الباحثين في إجراء البحث في منشآتكم، مع مراعاة الأتي:

١. اتباع قوانين اللجنة الوطنية للأخلاقيات الحيوية والطبية.
٢. في حال أي تغيير في خطة البحث يجب الحصول على موافقة إدارة الأبحاث.
٣. عدم تأثير الخدمة في المرافق المعنية.
٤. المحافظة على حقوق الأشخاص الخاضعين للبحث وخصوصيتهم.
٥. استخدام المعلومات لأغراض البحث العلمي فقط.
٦. تقديم تقرير عن سير الدراسة لإدارة البحوث كل ستة أشهر.

شاكرين تعاونكم.

وتفضلوا بقبول أطيب تحياتي،،

مساعد مدير الشؤون الصحية
للتخطيط والتحول

مدير إدارة البحوث والدراسات

د / ع

Email: Research

Tel#: [Redacted]

الرقم: ٠٠٠٧١٠ / ١٤٤٠ / ٤٧ ج التاريخ: ١٥ / ١٠ / ١٤٤٠ هـ المشفوعات:

Research and studies Department

IRB registration Number with KACST, KSA: H-02-J-002
Date:08/10/1440 Research Number: 01057

الموافقة للملائمة للشروط وللجنة الأخلاقيات - Initial Approval with Conditional

The Principle Investigator (PI)	Abeer Samir Jamal	اسم الباحث الرئيس
Submission Date	18/09/1440	تاريخ التقديم
Research Title	The Physical Therapists' and Parents experiences, views, and perceptions of Family-centred Care for children with physical disabilities in Saudi Arabia: A Qualitative Approach	عنوان البحث

The above titled research / study proposal has been examined with the following end closures: The study Protocol, ethics and Questionnaire.
The IRB recommended granting permission of approval to conduct the project along the following terms:

1. The PI and investigators are responsible to get permission from the head of department or unit in the institution to commence data collection.
2. The Investigator will conduct the study under the direct supervision by Supervisor of nursing research unit in nursing administration
3. Provide IRB "Continuing Review Progress Report" every 6 month.
4. Any amendments to the Approved Protocol or any element of the submitted documents should NOT be under taken without prior re-submission to, and approval of the IRB for prior approval.
5. Monitoring: The Project may be subject to audit or any other form of monitoring by the IRB.
6. The PI is responsible for the storage and retention of original data of the study for a minimum period of five years.
7. The PI is expected to submit a final report at the end of the study.
8. The PI must provide to IRB a conclusion abstract and the manuscript before Published.
9. The PI and researchers are required to have current and valid certificate on protective human research subjects.
10. The final approval letter with the IRB number will be given to the IP after he complete all the above terms and conditions
11. To follow all regulation issued by the National Committee of bio med ethics - King Abdul Aziz city for science and technology.

The organization and operating procedures of the research and study Administration - Directorate of health Affairs - Jeddah - Institutional review board (IRB) are based on the good clinical Practice, (GCP) Guidelines.

PLEASE NOTE THAT THIS APPROVAL IS VALID FOR ONE YEAR COMMENCING FROM THE DATE OF THIS LETTER.

I Read and Agree to the Above and take full responsibility
Signature :

تمت مراجعة المشروع المذكور للمحتويات الاتية: البروتوكول، الاستبيان واخلاقيات البحث العلمي.
توصي لجنة اخلاقيات البحث العلمي بالموافقة لإجراء المشروع على أساس الشروط التالية:

1. على الباحث الرئيسي والباحثين المشاركين الحصول على إذن من رئيس المنشأة للبدء بجمع البيانات المطلوبة للمشروع.
2. سيقيم الباحثين بإجراء الدراسة تحت إشراف مباشر من مشرف وحدة البحوث بإدارة التمريض بصحة جيدة.
3. يقوم الباحث بتقديم تقرير كل 6 أشهر عن آخر ما تم تنفيذه في المشروع.
4. أي تعديل على بروتوكول المشروع أو أي من الوثائق المقدمة مسبقاً يجب الحصول على موافقة للجنة قبل البدء في التنفيذ.
5. الموافقة: يمكن للمشروع أن يخضع للمراجعة أو أي نوع من المراقبة من قبل اللجنة الأخلاقية أثناء تنفيذ المشروع.
6. الباحث الرئيسي هو المسؤول عن حفظ البيانات الأصلية لمدة لا تقل عن خمس سنوات من إجراء المشروع.
7. المتوقع من الباحث أن يقدم تقريراً نهائياً في نهاية المشروع.
8. يجب على الباحث تقديم ملخص الدراسة ونسخة من المخطوطة قبل القيام بالنشر في المجلات العلمية.
9. يجب على الباحث الرئيسي والباحثين المشاركين الحصول على شهادة اخلاقيات البحث العلمي حديثة وسارية.
10. يحصل الباحث على خطاب الموافقة النهائي ورقم الموافقة من اللجنة الأخلاقية بعد قيام الباحثين باستكمال الشروط السابق ذكرها.
11. على الباحثين اتباع الأنظمة والقوانين الصادرة من اللجنة الوطنية لأخلاقيات الطب الحيوي بمدينة الملك عبد العزيز للعلوم والتقنية. إن اللوائح التنظيمية والتشغيلية للجنة الأخلاقية التابعة لإدارة البحوث والدراسات في صحة جدة تستند على الممارسة السريرية الجيدة، (GCP) Guidelines.

ملاحظة: هذه الموافقة المعيارية صالحة لمدة عام من تاريخ الصلور.

لغات واولى على ما سبق واتحمل كامل المسؤولية
التوقيع :

Dr/H.
Chairman of

Appendix C: Ethical approval from Private/Charitable Centre

Date: 28th May 2019

To: CARDIFF UNIVERSITY
U.K. School of Health Care Science

From: DR. [REDACTED]
General Director
[REDACTED]
[REDACTED], Saudi Arabia

[REDACTED], Saudi Arabia agreed to accept Mrs. ABEER SAMIR JAMAL to conduct and collect her PhD Research in the Center and we are going to distribute and collect her questionnaire to the parents on her behalf.

Please send us an official letter if you agree.

Appendix D: Study invitation (In English)



Are you a physical therapist who's treating children with physical disabilities?

Are you a parent of a child with physical disabilities?



All you have to do is to sit with the researcher and confidentially discuss your views and experiences of the rehabilitation services provided to the children.

You are invited to participate in my research that aims to improve the rehabilitation services for children with physical disabilities

If you would like to participate in the study kindly contact the researcher:

Name: Abeer Jamal

Phone:

Email:



Appendix E: Study invitation (In Arabic)



هل أنت أخصائي علاج طبيعي تعالج اطفال لديهم مشاكل حركية؟
هل لديك طفل يعاني من مشاكل حركية ويتلقى العلاج



كل ما عليكم فعله هو تخصيص من وقتكم للجلوس والتحدث بسرية تامة عن بعض المسائل المتعلقة بالرعاية الصحية التي تقدموها لمرضاكم أو التي يتلقاها أطفالكم في عيادات العلاج الطبيعي.



أنتم مدعوون للمشاركة
مشروعى البحثى المو
لتحسين الخدمات الصحية
المقدمة للاطفال ذوي المشاكل
الحركية فى المملكة العربية
السعودية.



فى حال لديكم الرغبة فى المشاركة، فضلاً لا أمراً التواصل على عناوين الاتصال التالية:
أ. عبير جمال
الهاتف:
البريد الإلكتروني:

“PHYSIOTHERAPISTS AND MOTHERS LIVED EXPERIENCES OF FAMILY-CENTRED CARE FOR CHILDREN WITH PHYSICAL DISABILITIES IN SAUDI ARABIA: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS”

English	Category	عربي
<ul style="list-style-type: none"> • Tell me about yourself? • How old are you? • What is your position in this organization? • How many years of experience do you have? • Tell me about your clinical background? • What are your cultural and religious background? 	<p>Demographics <i>معلومات عامة</i></p>	<p>هل يمكنك باختصار تقديم نفسك لي؟ كم عمرك؟ ما هو منصبك في هذه المنظمة؟ كم سنة من الخبرة لديك؟ هل يمكنك التحدث باختصار عن خبرتك الإكلينيكية؟ خلفيتك الثقافية والدينية؟</p>
<ul style="list-style-type: none"> • Tell me more about the physiotherapy care provided in this centre? • Tell me more about your own practice? • How do you provide care to children and their families? 	<p>The Physiotherapy care provided in centres <i>خدمة العلاج الطبيعي المقدمة في المراكز</i></p>	<p>هل يمكن أن تخبرني عن خدمات العلاج الطبيعي المقدمة في هذا المركز؟ أخبرني أكثر عن ممارستك الخاصة؟ هل يمكنك أن تعطيني بعض الأمثلة عن كيفية توفيرك و تقديمك الرعاية للأطفال في المركز</p>
<ul style="list-style-type: none"> • Have you heard of the term family-centred care? If so, what does it mean to you? • If not, what do you think it would mean? 	<p>The concept of Family-centred care <i>مفهوم الرعاية المتمركزة حول الأسرة</i></p>	<p>هل سمعت/ سمعتي بمصطلح الرعاية التي تركز على الأسرة؟ إذا كان الأمر كذلك ، ماذا يعني لك/لكي هذا المصطلح؟ إذا لم يكن الأمر كذلك ، فماذا تعتقد/ تعتقدن معناه</p>

<ul style="list-style-type: none"> • How do you use family centred care in your practice? • If so, could you give me examples of how you do this? • If not, how do you think it is different from your care? 	<p>Implementing FCC in practice تطبيق مفهوم (الرعاية المتمركزة حول الأسرة) في الممارسات الطبية</p>	<p>هل تستخدم مبدأ الرعاية المتمركزة حول الأسرة في ممارستك الطبية؟</p> <p>إذا كان الأمر كذلك ، هل يمكن أن تعطيني أمثلة على كيفية قيامك بذلك؟</p> <p>إذا لم يكن الأمر كذلك ، كيف تعتقد أنه يختلف عن رعايتك؟</p>
<ul style="list-style-type: none"> • Do you think the parent has an important role in physiotherapy? • What do you think about working in collaboration with parents? • Do you think collaborating with the whole family is important in physiotherapy? • How do you involve parents in the child's treatment plan and decision making? Give me an example. 	<p>Role of family and family involvement in rehabilitation دور الأسرة و مشاركة الأسرة في إعادة تأهيل الطفل</p>	<p>هل تعتقد أن للأهل دور مهم في العلاج الطبيعي؟</p> <p>ما رأيك في التعاون مع أولياء الأمور؟</p> <p>هل تعتقد أن التعاون مع جميع أفراد الأسرة أمر مهم في العلاج الطبيعي؟</p> <p>كيف تشرك الأهل في خطة علاج الطفل وصنع القرار؟ أعطني مثال.</p>
<ul style="list-style-type: none"> • What do you think about working in collaboration with other healthcare providers? 	<p>Collaboration with other healthcare staff التعاون مع موظفي الرعاية الصحية الآخرين</p>	<p>ما رأيك في العمل بالتعاون مع مقدمي الرعاية الصحية الآخرين؟</p>
<ul style="list-style-type: none"> • What do you think about communication and information sharing with parents? • Tell me a story from your experience where this generally works well? • Tell me a story from your experience where this does not work well? • How do you support child and families? 	<p>The provision of information And support توفير المعلومات والدعم</p>	<p>ما رأيك في التواصل وتبادل المعلومات مع أولياء الأمور؟</p> <p>أخبرني بقصة من تجربتك حيث يعمل هذا بشكل جيد بشكل عام؟</p> <p>أخبرني قصة من تجربتك حيث لا يعمل هذا بشكل جيد؟</p> <p>كيف تدعم الطفل والأسر؟</p>

<ul style="list-style-type: none"> • What challenges do you believe are affecting the provision of physiotherapy services? • Tell me an example of a specific situation where you have faced such challenge? • Tell me a solution from your own experience to overcome these challenges? 	<p>Challenges and barriers to care provision.</p> <p>التحديات والعقبات التي تحول دون توفير الرعاية</p>	<p>ما هي التحديات التي تعتقد أنها تؤثر على توفير خدمات العلاج الطبيعي؟</p> <p>أخبرني مثال على موقف معين واجهت فيه هذا التحدي؟</p> <p>أخبرني حلاً من تجربتك الخاصة للتغلب على هذه التحديات؟</p>
<p>How do you think services can be improved?</p> <p>Is there anything else that you would like to add or further discuss?</p> <p>كيف تعتقد أنه يمكن تحسين الخدمات؟ هل هناك أي شيء آخر تود إضافته أو مناقشته؟</p>		

“PHYSIOTHERAPISTS AND MOTHERS LIVED EXPERIENCES OF FAMILY-CENTRED CARE FOR CHILDREN WITH PHYSICAL DISABILITIES IN SAUDI ARABIA: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS”

English	Category	عربي
<ul style="list-style-type: none"> • Tell me about you and your family? • How old are you? • How many children do you have? • Do you work? • What are your cultural and religious background? 	<p align="center">Demographics</p> <p align="center"><i>معلومات عامة</i></p>	<p>هل يمكنك باختصار تقديم نفسك لي؟</p> <p>كم عمرك؟</p> <p>كم طفلا لديك؟</p> <p>هل تعمل/ تعملين؟</p> <p>هل يمكنك التحدث باختصار عن خلفيتك الثقافية والدينية؟</p>
<ul style="list-style-type: none"> • What care was provided for your child and family by the physiotherapist? • How was care provided? • Can you give some examples of how the care of your child has been provided? • What did you value most about the care given? 	<p align="center">The Physiotherapy care provided in centres</p>	<ul style="list-style-type: none"> • ما هي الرعاية المقدمة لطفلك وعائلتك من قبل المعالج الفيزيائي؟ • كيف تم توفير الرعاية؟ • هل يمكنك إعطاء بعض الأمثلة عن كيفية تقديم خدمات العلاج الطبيعي لطفلك؟ • ما أكثر ما يقدرونه في الرعاية المقدمة لهم؟

<ul style="list-style-type: none"> • Have you heard of Family-centred care? • If yes, what do you understand it means? • If not, what do you think it might mean? 	<p style="text-align: center;"><i>The concept of Family-centred care</i></p>	<p>هل سمعت/ سمعتي بمصطلح الرعاية التي تركز على الأسرة ؟</p> <p>إذا كانت الإجابة بنعم ، ما الذي تفهمه من معنى المصطلح؟</p> <p>إذا لم يكن الأمر كذلك ، فماذا تعتقد/ تعتقدن معناه؟</p>
<ul style="list-style-type: none"> • Have you been treated like this – if yes ask for examples • If no, how have you been treated? 	<p style="text-align: center;"><i>Implementing FCC in practice</i></p>	<p>هل عوملت بهذه الطريقة - إذا كانت الإجابة بنعم ، اسأل عن أمثلة</p> <p>إذا كانت الإجابة لا ، كيف تم علاجك؟</p>
<ul style="list-style-type: none"> • What was your role in your child's care? • How where you included? • Do you think that you have an important role in your child's treatment? • Do you feel you should be included in care of your child more? • Do you feel you should be more involved in the decisions concerning your child's treatment plan? 	<p style="text-align: center;"><i>Role of family and family involvement in rehabilitation</i></p>	<p>ما هو دورك في رعاية طفلك؟</p> <p>كيف شملت في الرعاية ؟</p> <p>هل تعتقد أن لديك دورًا مهمًا في علاج طفلك؟</p> <p>هل تشعر أنه يجب عليك أن تشمل في رعاية طفلك أكثر؟</p> <p>هل تشعر أنك يجب أن تكون أكثر اشتراكًا في القرارات المتعلقة بخطة علاج طفلك؟</p>
<ul style="list-style-type: none"> • What do you think about the collaboration between the different therapist treating your child? 	<p style="text-align: center;"><i>Collaboration with other healthcare staff</i></p>	<p>ما رأيك في التعاون بين المعالجين المختلفين الذين يقدمون العلاج طفلك؟</p>

<ul style="list-style-type: none"> • How do you feel about the communication and information sharing between you and your child's physiotherapists? • Do you think you need more information? • Do you think you need more support? • What information were given? • What support were you offered? 	<p><i>The provision of information And support</i></p>	<p>ما هو شعورك حيال التواصل وتبادل المعلومات بينك وبين المعالجين لطفلك؟ هل تعتقد أنك بحاجة إلى المزيد من المعلومات؟ هل تعتقد أنك بحاجة إلى المزيد من الدعم؟ ما هي المعلومات التي قدمت لك؟ ما هو الدعم الذي عرض عليكم؟</p>
<p>كيف تعتقد أنه يمكن تحسين الخدمات؟ هل هناك أي شيء آخر تود إضافته أو مناقشته؟</p>		

Appendix H: Consent form (In English)

Appendix II

Appendix II

Participant Consent form



Physiotherapists And Mothers Lived Experiences of Family-Centred Care For Children With Physical Disabilities In Saudi Arabia: An Interpretative Phenomenological Analysis

Name of Chief/Principle Investigator: Abeer Samir Jamal

Please Initial box

1. I confirm that I have read the information sheet dated 17 April 2019, version 1.0 for the above study. I have had the opportunity to consider that information, ask questions, and have had these answered satisfactory
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.
3. I understand that the interviews will be audio-recorded and will be listened to by the researcher
4. I understand that all information arising from the study will be treated as confidential and anonymity will be maintained.
5. I consent to the use of the anonymised data for publications or research presentations
6. I understand that all data recorded including interview recording and consent forms will be stored securely for a maximum of 5 years following the end of the study, then destroyed.
7. I agree to take part in the above study

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

Version 1.0

17 April 2019

Appendix I: Consent form (In Arabic)



Participant Consent form In Arabic

وقفة للموظف للمشاركة

تجارب أخصائي علاج لطبوعي وأنها أمور النقال ذو العلقة لحركية حول خدمات علاج
 لطبوعي لتقديمه للطفل ذو العلقة لجسي قسي لمهنة لعيبة لصعوبة

للم باحث لعيبي: عيسر جمال

ضع أول حرف من اسمك وخطك

أؤيد أنني قد قرأت وقفة للموظف والمعلومات المذكورة في ١٧ يوليو ٢٠١٩، الصادر ١٠ الدرس أعلاه وقد فهمتني فرص
 للنظر في تلك المعلومات وطرح الأسئلة، ولقد كنت هذه اليلة مرضية

أدرك أن شراكتي طويجة ولأنني حرفي النصح ابغني أي قت دون بداء أي يجب، دون أن يتكلم
 شخصي لقلوبية

أدرك أن لا قبل لتسوية معي لاصوني ووفيت مع لي هه الباحث

أدرك أن جميع المعلومات المذكورة عن الدرسل صحت مع لي غي أو اسرية وتهيتم للخطا غي اضاء لهية

أؤلق غي لخدم ليليات مح هة لاجرد للفتور أو لاعروض للبعية

أدرك أن جميع ليليات الامن غي بدي لئتمس ليل للقبلة ولتدارات الموقفة غي هه ليليات غي ليليات
 امن مدة قصا هه اعني يجب قاء الدرسل هه ليليات غي ليليات

أؤلق غي لشارك قسي الدرسل أعلاه

لتوقيع

لتاريخ

للم الباحث

لتوقيع

لتاريخ

للم الباحث

Appendix J: Participant information sheet for physiotherapists (In English)

Study Title

“PHYSIOTHERAPISTS AND MOTHERS LIVED EXPERIENCES OF FAMILY-CENTRED CARE FOR CHILDREN WITH PHYSICAL DISABILITIES IN SAUDI ARABIA: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS”

You are invited to take part in our study. Before you make the decision on whether to participate in our study, you need to understand the reasons why this study is being conducted. Please take time to read the following information carefully and if something is not clear or you need more information, please ask the main researcher for assistance.

What is the purpose of the study?

To explore your lived experiences of family-centred care (FCC) for the rehabilitation of children with physical disabilities. Understanding these experiences will help in providing a better rehabilitation services that meets the needs of the child and family.

Why have I been invited to participate?

You have been invited to participate because you are a physiotherapist that provide care for children with disabilities.

Do I have to take part in the study?

Participating in this study is completely voluntarily. You can choose whether to take part or not. If you decide to be involved, you will be given this information sheet to keep and after you have had enough time to read through it, you can contact the researcher (Abeer Jamal) to confirm participation and to set the day and date of the interview. Please note that you have the right to withdraw from the study at any time without giving a reason or providing explanation. Please be assured that taking part in this study or even withdrawing from it will not affect your employment status.

What will happen if I take part in the study?

You will be invited to participate in one-to-one interview with the researcher at your own convenient time. The interview will be held in a quiet and private place at the rehabilitation centre. It will include questions about your experience of FCC and rehabilitation services for children with physical disabilities. Interviews will last an hour and will be audio-taped. The recordings will be listened to by the researcher only.

What are the possible benefits of taking part?

Taking part in this study will be beneficial for you as a healthcare provider as It will help us better understand your lived experiences of the rehabilitation services given to children with physical disabilities. This will assist in identifying the gaps in care provided and in return, help physiotherapists to deliver services that meets the need of the child and family.

Will my taking part in the study remain confidential?

As a research student at Cardiff University in the United Kingdom, I will handle, process, store, and destroy all information collected in accordance with the General Data Protection Regulation (GDPR) 2016. The GDPR require that all information collected about you during the study will be kept strictly confidential. Your interview transcript will be anonymised (initials will be used instead of names) and the paper-based consent forms bearing names will be stored confidentially and securely at each rehabilitation centre. Data will be seen and discussed with the researcher's supervisors. After the study is completed, the information gathered will be destroyed in a safe and secure way.

What will happen to the results of the study?

The outcomes of this study will be reported in the form of a PhD thesis that will be stored in the Library at Cardiff University. A summary of the results may be reported at professional meetings and in publications, but participants' names will be anonymised.

Who is organising and funding the study?

The study is part of a PhD thesis, in which the researcher is a scholar student funded by King Abdul-Aziz University represented in the Royal Embassy of Saudi Arabia Cultural Bureau in London.

What if something goes wrong?

You will be asked to comply with instructions given to you during the study and to cooperate fully with the researcher. If you are harmed due to someone's negligence, then you may have grounds for a legal action, but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during this study and would like to talk to someone independent to the study please contact: [redacted] Director of Research Governance, School of Healthcare Sciences: [redacted]

Who has reviewed and approved the study?

This study is approved by Cardiff University School of Healthcare Sciences Ethics Committee. The study was also approved by the Saudi Ministry of Health and by the private rehabilitation centres included in the study.

What do I do now?

Thank you for your time in reading this information sheet. If you require further information to make an informed decision about whether to participate in the study, please do not hesitate to contact me Abeer Jamal (the researcher) on [redacted]

Appendix K: Participant information sheet for physiotherapists (In Arabic)



ورقة المعلومات

عنوان الدراسة:

أمور الأطفال ذو الإعاقَة الحركية حول خدمات العلاج الطبيعي المقدمة للطفل ذو الإعاقَة وأولياء تجارب أخصائي العلاج الطبيعي الجسدية في المملكة العربية السعودية. أنت مدعو للمشاركة في دراستنا ولكن قبل اتخاذ القرار بشأن ما إذا كنت تريد المشاركة في دراستنا، عليك أن تفهم سبب إجراء هذه الدراسة. يرجى أخذ الوقت الكافي لقراءة المعلومات التالية بعناية، وإذا كان هناك أي شيء غير واضح أو كنت بحاجة إلى مزيد من المعلومات يرجى عدم التردد في طلب المساعدة من الباحث الرئيسي

ما هو الغرض من الدراسة؟

لاستكشاف التجارب والخبرات التي يمر بها أخصائي العلاج الطبيعي فيما يتعلق بالعلاج الطبيعي للطفل في وضع التأهيل. هذه سيساعد ذلك الباحثين والعاملين في . وعائلته المعلومات ذات قيمة كبيرة لأنها سوف تعطي نظرة ثاقبة عن الرعاية المقدمة للطفل المجالات الصحية في المستقبل على تحسين الخدمات الصحية المقدمة لهذه الفئة بحيث تلبي احتياجات الطفل والأسرة

لماذا دعيت للمشاركة؟

وتستطيع المشاركة الحركية، أنت مدعو للانضمام إلى هذه الدراسة لأنك أخصائي علاج طبيعي تقوم بمعالجة الأطفال ذوي الإعاقَة وابداء رأيك فيما يتعلق بخدمات العلاج الطبيعي

المشاركة؟ على هل يجب

المشاركة في هذه الدراسة طوعية تمامًا. يمكنك اختيار المشاركة أو عدم المشاركة. إذا قررت المشاركة، سيتم إعطاؤك ورقة المعلومات هذه للاحتفاظ بها وبعد أن يكون لديك الوقت الكافي لقراءتها، يمكنك الاتصال بالباحث (عبير جمال) لتأكيد المشاركة ولتحديد يوم وتاريخ المقابلة. يرجى ملاحظة أن لديك الحق في الانسحاب من الدراسة في أي وقت دون إبداء سبب أو تقديم تفسير. يرجى التأكد من أن كأخصائي علاج طبيعي المشاركة في هذه الدراسة أو حتى الانسحاب منها لن يؤثر على عملك

ماذا سيحدث لي إذا شاركت؟

في سوف يتم دعوتك إلى المشاركة في المقابلات الشخصية مع الباحث في الوقت المناسب لك. المقابلات ستعقد في مكان هادئ وخاص حرصا على خصوصيتكم. المقابلة ستضمن أسئلة حول خدمات العلاج الطبيعي المقدمة للأطفال ذوي الإعاقات الحركية. مركز التأهيل ستدوم المقابلة لمدة ساعة وسيتم تسجيل المقابلات صوتيا. التسجيل الصوتي سوف يتم الاستماع إليه من قبل الباحث الرئيسي فقط ولذلك لأغراض البحث العلمي.

ما هي فوائد المشاركة

الإعاقات الحركية. سيساعدنا ذلك على فهم خبراتك بشكل ستكون المشاركة في هذه الدراسة مفيدة لك كمقدم رعاية صحية للأطفال ذوي يساعد المقابل، سيساعد ذلك على تحديد نقاط الضعف في الرعاية المقدمة وفي . للطفل أفضل فيما يتعلق بخدمات إعادة التأهيل المقدمة أخصائي العلاج الطبيعي على تقديم الخدمات التي تلبي احتياجات الطفل والأسرة

هل سيظل مشاركتي في الدراسة سرية؟

كطالبة باحثة في جامعة كارديف بالمملكة المتحدة، سأقوم بمعالجة ومعالجة وتخزين جميع المعلومات التي تم جمعها وفقًا للائحة العامة (GDPR 2016). لحماية البيانات

والتي تنص على الاحتفاظ بالمعلومات التي جمعها بسرية حيث سيتم إخفاء اسمك بنسخة المقابلة والاكتماء بوضع رموز حرفية. سيتم سيتم الاطلاع على البيانات ومناقشتها مع . تخزين نماذج الموافقة الورقية التي تحمل اسمك بسرية وأمان في كل مركز إعادة التأهيل وبعد الانتهاء من الدراسة، سيتم التخلص من المعلومات التي تم جمعها بطريقة آمنة. الدراسيين للباحث المشرفين

ماذا سيحدث لنتائج الدراسة؟

سيتم عرض نتائج هذه الدراسة في أطروحة الدكتوراه والتي سيتم تخزينها في مكتبة جامعة كارديف. سيتم مشاركة ملخص البحث والنتائج في المؤتمرات العلمية والمهنية، ولكن لن يتم الكشف عن أسماء المشاركين.

من ينظم ويمول الدراسة؟

الدراسة جزء من أطروحة الدكتوراه، حيث أن الباحث موظف مبتعث من جامعة الملك عبدالعزيز و ممول من قبل الملحقة الثقافية السعودية في لندن.

ماذا لو حدث خطأ ما؟

سيطلب منك الالتزام بالتعليمات المقدمة لك أثناء الدراسة والتعاون الكامل مع الباحث. إذا تعرضت لأذى بسبب إهمال شخص ما، فقد أو يكون لديك أسباب لاتخاذ إجراء قانوني، ولكن قد تضطر إلى دفع ثمنه. بصرف النظر عن هذا، إذا كنت ترغب في تقديم شكوى، وترغب في ذلك للتحدث إلى لديك أي مخاوف بشأن أي جانب من جوانب الطريقة التي تم تناولك بها أو معالجتها أثناء هذه الدراسة،:شخص مستقل عن الدراسة، يرجى الاتصال مديرة إدارة البحوث، كلية علوم الرعاية الصحية

من قام بمراجعة واعتماد الدراسة؟

تمت الموافقة على الدراسة من قبل .تمت الموافقة على هذه الدراسة من قبل لجنة أخلاقيات البحث بكلية العلوم الصحية بجامعة كارديف.وزارة الصحة السعودية ومراكز إعادة التأهيل الخاصة المدرجة في الدراسة للمزيد من المعلومات وتفاصيل الاتصال

:إذا كان لديك أي مخاوف أو أسئلة أخرى حول الدراسة، يرجى عدم التردد في الاتصال بالشخص التالي
عبير جمال على عبر البريد الإلكتروني على

نشكرك على قراءة ورقة المعلومات هذه

Appendix L: Participant Information Sheet for Mothers (in English)

Participants Information Sheet for Parents

Study Title

“PHYSIOTHERAPISTS AND MOTHERS LIVED EXPERIENCES OF FAMILY-CENTRED CARE FOR CHILDREN WITH PHYSICAL DISABILITIES IN SAUDI ARABIA: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS”

You are invited to take part in our study. Before you make the decision on whether to participate in our study, you need to understand the reasons why this study is being conducted. Please take time to read the following information carefully and if something is not clear or you need more information, please ask the main researcher for assistance.

What is the purpose of the study?

To explore your experiences of Family-centred care (FCC) for the rehabilitation of your child with physical disability. Understanding these experiences will help in providing a better rehabilitation services that meets the needs of the child and family.

Why have I been invited to participate?

You have been invited to participate because you are a parent of a child with a physical disability.

Do I have to take part in the study?

Participating in this study is completely voluntarily. You can choose whether to take part or not. If you decide to be involved, you will be given this information sheet to keep and after you have had enough time to read through it, you can contact the researcher (Abeer Jamal) to confirm participation and to set the day and date of the interview. Please note that you have the right to withdraw from the study at any time without giving a reason or providing explanation. Please be assured that taking part in this study or even withdrawing from it will not affect your child’s treatment plan at the facility.

What will happen if I take part in the study?

You will be invited to participate in one-to-one interview with the researcher at your own convenient time. The interview will be held in a quiet and private place at the rehabilitation centre. It will include questions about your experience of FCC and rehabilitation services for your child with physical disability. Interviews will last an hour and will be audio-taped. The recordings will be listened to by the researcher only.

What are the possible benefits of taking part?

Taking part in this study will be beneficial for you as a parent will help us better understand your experiences of the rehabilitation services given to you child with physical disability. This will assist in identifying the gaps in care provided and in return, help physiotherapists to deliver services that meets the need of the child and family.

Will my taking part in the study remain confidential?

As a research student at Cardiff University in the United Kingdom, I will handle, process, store, and destroy all information collected in accordance with the General Data Protection Regulation (GDPR) 2016. The GDPR require that all information collected about you during the study will be kept strictly confidential. Your interview transcript will be anonymised (using initials) and the paper-based consent forms bearing names will be stored confidentially and securely at each rehabilitation centre. Data will be seen and discussed with the researcher's supervisors. After the study is completed, the information gathered will be destroyed in a safe and secure way.

What will happen to the results of the study?

The outcomes of this study will be reported in the form of a PhD thesis that will be stored in the Library at Cardiff University. A summary of the results may be reported at professional meetings and in publications, but participants' names will be anonymised.

Who is organising and funding the study?

The study is part of a PhD thesis, in which the researcher is a scholar student funded by King Abdul-Aziz University represented in the Royal Embassy of Saudi Arabia Cultural Bureau in London.

What if something goes wrong?

You will be asked to comply with instructions given to you during the study and to cooperate fully with the researcher. If you are harmed due to someone's negligence, then you may have grounds for a legal action, but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during this study and would like to talk to someone independent to the study please contact: Dr. [REDACTED], Director of Research Governance, School of Healthcare Sciences: [REDACTED]

Who has reviewed and approved the study?

This study is approved by Cardiff University School of Healthcare Sciences Ethics Committee. The study was also approved by the Saudi Ministry of Health and by the private rehabilitation centres included in the study.

What do I do now?

Thank you for your time in reading this information sheet. If you require further information to make an informed decision about whether to participate in the study, please do not hesitate to contact me Abeer Jamal (the researcher) on [REDACTED]

ورقة المعلومات

عنوان الدراسة:

أمور الأطفال ذوو الإعاقة الحركية حول خدمات العلاج الطبيعي المقدمة للطفل ذو الإعاقة وأولياء تجارب أخصائي العلاج الطبيعي الجسدية في المملكة العربية السعودية

أنت مدعو للمشاركة في دراستنا ولكن قبل اتخاذ القرار بشأن ما إذا كنت تريد المشاركة في دراستنا، عليك أن تفهم سبب إجراء هذه الدراسة. يرجى أخذ الوقت الكافي لقراءة المعلومات التالية بعناية، وإذا كان هناك أي شيء غير واضح أو كنت بحاجة إلى مزيد من المعلومات يرجى عدم التردد في طلب المساعدة من الباحث الرئيسي

ما هو الغرض من الدراسة؟

أهالي الطفل ذو الإعاقة الحركية فيما يتعلق بالعلاج الطبيعي للطفل في وضع التأهيل. هذه لاستكشاف التجارب والخبرات التي يمر بها سيساعد ذلك الباحثين والعاملين في. وعائلته المعلومات ذات قيمة كبيرة لأنها سوف تعطي نظرة ثاقبة عن الرعاية المقدمة للطفل المجالات الصحية في المستقبل على تحسين الخدمات الصحية المقدمة لهذه الفئة بحيث تلبي احتياجات الطفل والأسرة

لماذا دعيت للمشاركة؟

أنت مدعو للانضمام إلى هذه الدراسة لأنك والد أو والد طفلة مصاب بإعاقة حركية، وتستطيع المشاركة وابداء رأيك فيما يتعلق بعلاج طفلك

المشاركة؟ على هل يجب

المشاركة في هذه الدراسة طوعية تمامًا. يمكنك اختيار المشاركة أو عدم المشاركة. إذا قررت المشاركة، سيتم إعطاؤك ورقة المعلومات هذه للاحتفاظ بها وبعد أن يكون لديك الوقت الكافي لقراءتها، يمكنك الاتصال بالباحث (عبير جمال) لتأكيد المشاركة ولتحديد يوم وتاريخ المقابلة. يرجى ملاحظة أن لديك الحق في الانسحاب من الدراسة في أي وقت دون إبداء سبب أو تقديم تفسير. يرجى التأكد من أن الصحية المشاركة في هذه الدراسة أو حتى الانسحاب منها لن تؤثر على خطة علاج طفلك في المنشأة

ماذا سيحدث لي إذا شاركت؟

في سوف يتم دعوتك إلى المشاركة في المقابلات الشخصية مع الباحث في الوقت المناسب لك. المقابلات ستعقد في مكان هادئ وخاص حرصا على خصوصيتكم. المقابلة ستضمن أسئلة حول خدمات العلاج الطبيعي المقدمة للأطفال ذوي الإعاقات الحركية. مركز التأهيل ستدوم المقابلة لمدة ساعة وسيتم تسجيل المقابلات صوتيا. التسجيل الصوتي سوف يتم الاستماع إليه من قبل الباحث الرئيسي فقط ولذلك لأغراض البحث العلمي

ما هي فوائد المشاركة

سنتكون المشاركة في هذه الدراسة مفيدة لك كوالد أو والد طفلة من ذوي الإعاقات الحركية. سيساعدنا ذلك على فهم خبراتك بشكل أفضل يساعد أخصائي المقابل، سيساعد ذلك على تحديد نقاط الضعف في الرعاية المقدمة وفي للطفل فيما يتعلق بخدمات إعادة التأهيل المقدمة العلاج الطبيعي على تقديم الخدمات التي تلبي احتياجات الطفل والأسرة

الدراسة سرية؟ هل سيظل مشاركتي في

كطالبة باحثة في جامعة كارديف بالمملكة المتحدة، سأقوم بمعالجة ومعالجة وتخزين جميع المعلومات التي تم جمعها وفقاً للائحة العامة (GDPR 2016) لحماية البيانات والتي تنص على الاحتفاظ بالمعلومات التي جمعها بسرية حيث سيتم إخفاء اسمك بنسخة المقابلة والاكتماء بوضع رموز حرفية. سيتم سيتم الاطلاع على البيانات ومناقشتها مع . تخزين نماذج الموافقة الورقية التي تحمل اسمك بسرية وأمان في كل مركز إعادة التأهيل بعد الانتهاء من الدراسة، سيتم التخلص من المعلومات التي تم جمعها بطريقة آمنة. الدراسيين للباحث المشرفين

ماذا سيحدث لنتائج الدراسة؟

مكتبة جامعة كارديف. سيتم مشاركة ملخص البحث سيتم عرض نتائج هذه الدراسة في أطروحة الدكتوراه والتي سيتم تخزينها في والنتائج في المؤتمرات العلمية والمهنية، ولكن لن يتم الكشف عن أسماء المشاركين

من ينظم ويمول الدراسة؟
الدراسة جزء من أطروحة الدكتوراه، حيث أن الباحث موظف مبعث من جامعة الملك عبدالعزيز و ممول من قبل الملحقة الثقافية
السعودية في لندن

ماذا لو حدث خطأ ما؟

سيطلب منك الالتزام بالتعليمات المقدمة لك أثناء الدراسة والتعاون الكامل مع الباحث. إذا تعرضت لأذى بسبب إهمال شخص ما، فقد يكون لديك أسباب لاتخاذ إجراء قانوني، ولكن قد تضطر إلى دفع ثمنه. بصرف النظر عن هذا، إذا كنت ترغب في تقديم شكوى، أو لديك وترغب في ذلك للتحدث إلى شخص أي مخاوف بشأن أي جانب من جوانب الطريقة التي تم تناولك بها أو معالجتها أثناء هذه الدراسة، مستقل عن الدراسة، يرجى الاتصال بـ: مديرة إدارة البحوث، كلية علوم الرعاية الصحية أو هاتف

من قام بمراجعة واعتماد الدراسة؟

تمت الموافقة على الدراسة من قبل .تمت الموافقة على هذه الدراسة من قبل لجنة أخلاقيات البحث بكلية العلوم الصحية بجامعة كارديف
وزارة الصحة السعودية ومراكز إعادة التأهيل الخاصة المدرجة في الدراسة

للمزيد من المعلومات وتفاصيل الاتصال

:إذا كان لديك أي مخاوف أو أسئلة أخرى حول الدراسة، يرجى عدم التردد في الاتصال بالشخص التالي
عبر جمال علي، و عبر البريد الإلكتروني على

نشكرك على قراءة ورقة المعلومات هذه

Appendix N: Critical Appraisal Checklists



CASP Checklist: 10 questions to help you make sense of a **Qualitative** research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

- ▶ Are the results of the study valid? (Section A)
- ▶ What are the results? (Section B)
- ▶ Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA ‘Users’ guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

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Paper for appraisal and reference:

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- what was the goal of the research
 - why it was thought important
 - its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
 - Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

4. Was the recruitment strategy appropriate to the aims of the research?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
 - If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
 - If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
 - If methods were modified during the study. If so, has the researcher explained how and why
 - If the form of data is clear (e.g. tape recordings, video material, notes etc.)
 - If the researcher has discussed saturation of data

Comments:

6. Has the relationship between researcher and participants been adequately considered?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:

8. Was the data analysis sufficiently rigorous?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
 - To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider whether

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

Section C: Will the results help locally?

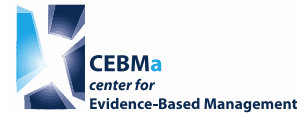
10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature)
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

Appendix O: the Critical Appraisal Checklist for Cross-Sectional Study



Critical Appraisal of a Cross-Sectional Study (Survey)

Appraisal questions	Yes	Can't tell	No
1. <i>Did the study address a clearly focused question / issue?</i>			
2. <i>Is the research method (study design) appropriate for answering the research question?</i>			
3. <i>Is the method of selection of the subjects (employees, teams, divisions, organizations) clearly described?</i>			
4. <i>Could the way the sample was obtained introduce (selection) bias?</i>			
5. <i>Was the sample of subjects representative with regard to the population to which the findings will be referred?</i>			
6. <i>Was the sample size based on pre-study considerations of statistical power?</i>			
7. <i>Was a satisfactory response rate achieved?</i>			
8. <i>Are the measurements (questionnaires) likely to be valid and reliable?</i>			
9. <i>Was the statistical significance assessed?</i>			
10. <i>Are confidence intervals given for the main results?</i>			
11. <i>Could there be confounding factors that haven't been accounted for?</i>			
12. <i>Can the results be applied to your organization?</i>			

Adapted from Crombie, *The Pocket Guide to Critical Appraisal*; the critical appraisal approach used by the Oxford Centre for Evidence Medicine, checklists of the Dutch Cochrane Centre, BMJ editor's checklists and the checklists of the EPPI Centre.

Cite as: Center for Evidence Based Management (July, 2014), Critical Appraisal Checklist for Cross-Sectional Study. Retrieved (month, day, year) from <https://www.cebma.org>

Appendix P: Procedure of Exclusion

Reasons for not using the bellow theories unlike IPA

Ethnography	Grounded Theory	Narrative Inquiry
<i>Direct discription of Culture and norms</i>	<i>The development of a theory</i>	<i>Story telling</i>
Produce knowledge rather than improve practice, and in my case, I would like to improve our practice of FCC as physiotherapists and not only our knowledge	Done when little is known about a topic, and in my case, FCC was explored in adulthood and pediatric care in Saudi Arabia and It is a well-known concept/ theory worldwide.	Experience of a particular situation (living with breast cancer), that represents the singular experience of an individual.
Time consuming as the researcher is totally emerged in the research setting	Sampling is an ongoing process throughout the research, which requires longer time to do it. In my PhD I'm limited to a 3 months period for data collection in Saudi Arabia as advised by the sponsor.	It is a story, with a begging, a middle, and an end, and in my case caring for a disabled child is a situation lived for ever, and changeable depending on the child's disability. There is no end to their suffering and their experiences and views can change e very single day.
	Doesn't aim for the truth and it is not an accurate descriptive method. It generates concepts that explains how people resolves their concerns regardless of time and place. Incident is all what matters in GT and not people perception or expe rience.	Recall bias/issues are major problems in narrative research. From my personal prospective (based on my MSc research), parents faced difficulties when trying to remember things happened over a year period of time. I bet that it is harder to remember things that happened 2 years ago or even more.

Appendix Q: Lone-worker policy



Lone worker policy

The researcher will follow Cardiff University **Working alone** Health and safety guidance on the risks of lone working. In which hazards, and potential risks related to conducting research outside the United Kingdom (in Saudi Arabia) are evaluated.

The researcher acknowledges that in case of violence, hazard, or urgent situation, help will be sought from the heads of physiotherapy departments at each centre/facility. The researcher will also keep the supervisors informed about such risks if present.

-----The policy can be found in the following page-----

Working alone

Health and safety guidance on the risks of lone working



This is a web-friendly version of leaflet INDG73(rev3), published 05/13

Introduction

This leaflet provides guidance on how to keep lone workers healthy and safe. It is aimed at anyone who employs or engages lone workers, and also at self-employed people who work alone.

Following the guidance in the leaflet is not compulsory, but it should help employers understand what they need to do to comply with their legal duties towards lone workers under:

- the Health and Safety at Work etc Act 1974;
- the Management of Health and Safety at Work Regulations 1999.

Is it legal to work alone and is it safe?

Working alone is not in itself against the law and it will often be safe to do so. However, the law requires employers to consider carefully, and then deal with, any health and safety risks for people working alone.

Employers are responsible for the health, safety and welfare at work of all their workers. They also have responsibility for the health and safety of any contractors or self-employed people doing work for them.

These responsibilities cannot be transferred to any other person, including those people who work alone.

Workers have responsibilities to take reasonable care of themselves and other people affected by their work activities and to co-operate with their employers in meeting their legal obligations.

Who are lone workers and what jobs do they do?

Lone workers are those who work by themselves without close or direct supervision, for example:

In fixed establishments

- A person working alone in a small workshop, petrol station, kiosk or shop
- People who work from home other than in low-risk, office-type work (separate guidance covers homeworkers doing low-risk work – see the end of the leaflet for details)
- People working alone for long periods, eg in factories, warehouses, leisure centres or fairgrounds
- People working on their own outside normal hours, eg cleaners and security, maintenance or repair staff

As mobile workers working away from their fixed base

- Workers involved in construction, maintenance and repair, plant installation and cleaning work
- Agricultural and forestry workers
- Service workers, including postal staff, social and medical workers, engineers, estate agents, and sales or service representatives visiting domestic and commercial premises

How must employers control the risks?

Employers have a duty to assess risks to lone workers and take steps to avoid or control risks where necessary. This must include:

- involving workers when considering potential risks and measures to control them;
- taking steps to ensure risks are removed where possible, or putting in place control measures, eg carefully selecting work equipment to ensure the worker is able to perform the required tasks in safety;
- instruction, training and supervision;
- reviewing risk assessments periodically or when there has been a significant change in working practice.

This may include:

- being aware that some tasks may be too difficult or dangerous to be carried out by an unaccompanied worker;
- where a lone worker is working at another employer's workplace, informing that other employer of the risks and the required control measures;
- when a risk assessment shows it is not possible for the work to be conducted safely by a lone worker, addressing that risk by making arrangements to provide help or back-up.

Risk assessment should help employers decide on the right level of supervision. There are some high-risk activities where at least one other person may need to be present. Examples include:

- working in a confined space, where a supervisor may need to be present, along with someone dedicated to the rescue role;
- working at or near exposed live electricity conductors;
- working in the health and social care sector dealing with unpredictable client behaviour and situations.

Employers who have five or more employees must record the significant findings of all risk assessments.

Employers also need to be aware of any specific law that prohibits lone working applying in their industry. Examples include supervision in diving operations, vehicles carrying explosives and fumigation work.

Further information about controlling risks can be found on the HSE website at: www.hse.gov.uk/toolbox/.

Further sources of information are listed at the end of the leaflet.

What must employers consult on?

By law, employers must consult all their employees on health and safety matters.

Effective consultation will also help ensure that relevant hazards are identified, and appropriate and proportionate control measures are chosen.

You can find more advice on HSE's website:
www.hse.gov.uk/toolbox/managing/consulting.htm.

Which particular problems affect lone workers?

Lone workers should not be put at more risk than other employees. Establishing a healthy and safe working environment for lone workers can be different from organising the health and safety of other employees. Some of the issues that need special attention when planning safe working arrangements are set out in the following pages, but your risk assessment process should identify the issues relevant to your circumstances.

Can one person adequately control the risks of the job?

Employers should take account of normal work and foreseeable emergencies, eg fire, equipment failure, illness and accidents. Employers should identify situations where people work alone and consider the following:

- Does the workplace present a specific risk to the lone worker, for example due to temporary access equipment, such as portable ladders or trestles that one person would have difficulty handling?
- Is there a safe way in and out for one person, eg for a lone person working out of hours where the workplace could be locked up?
- Is there machinery involved in the work that one person cannot operate safely?
- Are chemicals or hazardous substances being used that may pose a particular risk to the lone worker?
- Does the work involve lifting objects too large for one person?
- Is there a risk of violence and/or aggression?
- Are there any reasons why the individual might be more vulnerable than others and be particularly at risk if they work alone (for example if they are young, pregnant, disabled or a trainee)?
- If the lone worker's first language is not English, are suitable arrangements in place to ensure clear communications, especially in an emergency?

If a person has a medical condition, are they able to work alone?

Employers should seek medical advice if necessary. Consider both routine work and foreseeable emergencies that may impose additional physical and mental burdens on an individual.

Why is training particularly important for lone workers?

Training is particularly important where there is limited supervision to control, guide and help in uncertain situations.

Training may also be crucial in enabling people to cope in unexpected circumstances and with potential exposure to violence and aggression.

Lone workers are unable to ask more experienced colleagues for help, so extra training may be appropriate. They need to be sufficiently experienced and fully understand the risks and precautions involved in their work and the location that they work in.

Employers should set the limits to what can and cannot be done while working alone. They should ensure workers are competent to deal with the requirements of the job and are able to recognise when to seek advice from elsewhere.

How will the person be supervised?

The extent of supervision required depends on the risks involved and the ability of the lone worker to identify and handle health and safety issues.

The level of supervision needed is a management decision, which should be based on the findings of a risk assessment, ie the higher the risk, the greater the level of supervision required. It should not be left to individuals to decide whether they need assistance.

Where a worker is new to a job, undergoing training, doing a job that presents specific risks, or dealing with new situations, it may be advisable for them to be accompanied when they first take up the post.

Monitoring

Procedures must be put in place to monitor lone workers as effective means of communication are essential. These may include:

- supervisors periodically visiting and observing people working alone;
- pre-agreed intervals of regular contact between the lone worker and supervisor, using phones, radios or email, bearing in mind the worker's understanding of English;
- manually operated or automatic warning devices which trigger if specific signals are not received periodically from the lone worker, eg staff security systems;
- implementing robust system to ensure a lone worker has returned to their base or home once their task is completed.

What happens if a person becomes ill, has an accident, or there is an emergency?

Your assessment of the risks should identify foreseeable events. Emergency procedures should be established and employees trained in them.

Information regarding emergency procedures should be given to lone workers. Your risk assessment may indicate that mobile workers should carry first-aid kits and/or that lone workers need first-aid training. They should also have access to adequate first-aid facilities.

Find out more

Homeworkers: Guidance for employers on health and safety Leaflet INDG226(rev1)
HSE Books 2011 www.hse.gov.uk/pubns/indg226.pdf

*Manual handling. Manual Handling Operations Regulations 1992 (as amended).
Guidance on Regulations L23* (Third edition) HSE Books 2004
ISBN 978 0 7176 2823 0 www.hse.gov.uk/pubns/books/l23.htm

Violence at work: A guide for employers Leaflet INDG69(rev) HSE Books 1996
www.hse.gov.uk/pubns/indg69.pdf

Managing work-related violence in licensed and retail premises Leaflet INDG423
HSE Books 2008 www.hse.gov.uk/pubns/indg423.pdf

Working with substances hazardous to health: A brief guide to COSHH Leaflet
INDG136(rev5) HSE Books 2012 www.hse.gov.uk/pubns/indg136.htm

Working at height: www.hse.gov.uk/toolbox/height.htm

Other sources of advice: You may be able to get additional information from your trade association or employers' organisation, or from trade unions and some charities, eg the Suzy Lamplugh Trust.

Further information

For information about health and safety, or to report inconsistencies or inaccuracies in this guidance, visit www.hse.gov.uk/. You can view HSE guidance online and order priced publications from the website. HSE priced publications are also available from bookshops.

This guidance is issued by the Health and Safety Executive. Following the guidance is not compulsory, unless specifically stated, and you are free to take other action. But if you do follow the guidance you will normally be doing enough to comply with the law. Health and safety inspectors seek to secure compliance with the law and may refer to this guidance.

This leaflet is available at: www.hse.gov.uk/pubns/indg73.htm.

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Appendix R: an Example of the idiographic experiences- tables of Themes

This is just an example of the table of themes. The full idiographic experiences -tables of themes are Attached as supplementary material (a PDF document).

1. Hanaa

Superordinate Theme 1 - Family-Centred Care		
Subordinate theme	Quote	Line number
	<i>"What I guess is maybe I have maybe this vague idea that family is incorporated in the... ah... rehabilitation programme... ah... so it can be either because mostly over the past years and up till recently we are centre-based or school-based or community-based, and we just ignore the family, where this is the first place that needs attention."</i>	Lines 791 – 797
	<i>"The first time the mother... ah... learn how to, this is like a preparation like how to after this session, how you're going to deal with your child at home, so we are teaching all the home hands-on, actually hands-on, practice together with the supervision, so at least she is getting that confidence "okay this hand I'm doing correct"."</i>	Lines 318- 324
Superordinate Theme 2 - The Saudi Culture		
Subordinate theme	Quote	Line number

The impact of Saudi culture on role distribution	<i>"Because the culture here... what I noticed since all my experience, the mother is the one main carer, the father is just a provider, so most of the things they do not know, even though parents mean father and mother."</i>	Lines 184-188
Father's role in Saudi	<i>"Because the culture here... what I noticed since all my experience, the mother is the one main carer, the father is just a provider, so most of the things they do not know, even though parents mean father and mother."</i>	Lines 184-188
Mothers' role in Saudi	<i>"But you know the mothers say, "how can I deal with all, I have work at home, I have to take care of other children, I have to cook for the family, many things and have not only this job, I do not have anyone to help at home". So these are the complaints 80%, no not 80%, 90% of the mothers we heard it, so that is why I am saying here more mother is the caregiver."</i>	Lines 194-200
Culture as a barrier to Family-centred care	<i>"Because here the culture somehow the father also not coming, and you know sitting with the communities where all ladies are there, it is not very good"</i>	Lines 373- 375
	<i>"Because we are the ones talking about the family importance in the treatment plan, and we are the ones who are restricting the fathers to go inside, because of the culture. The thing is the therapists or the experts do not have any issues with</i>	Lines 384 – 390