THE VOICE OF CHILDREN WITH CEREBRAL PALSY (CP) AND THEIR MOTHERS IN SAUDI ARABIA

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ABSTRACT

This research reports the study conducted in Saudi Arabia, which aimed to explore: 1) the perception of the term CP with CP children and their mothers, 2) the implication of the meaning for mothers of children with CP, 3) the experiences of being a child with CP in Saudi Arabia.

A qualitative approach was taken using critical ethnography methodology, informed by Bronfenbrenner's (1989, 1992 & 2005) ecological theory framework. Data were collected in two phases: Phase one involved two focus group interviews with 6 mothers of children with CP and follow up semi-structured interviews with three of them. The second phase of the research focused on interviews with children with CP. Semi-structured interviews were conducted with 9 children ranging between 5-17 years of age. Talking Mats, an innovative communication tool, was used to enable two children with difficult verbal communication to give their views.

The findings of this study highlighted four main key issues: the influence of cultural perspectives, mixed with religious values, on mothers' perceptions of the term CP; the mother's role and the challenges faced within that role; the children's opportunity to express the opinions of their world; and finally community stigmatization and discrimination of children with CP and their mothers.

The evidence of this study indicates that children with CP and their mothers welcomed the opportunity to participate and to explore their experiences. It also indicated that the children's perception of their disability differ slightly from those of the mothers' views which tend to be considerably "normal child" or "delayed walking", or theological explanations. Most children were aware of their difference and impairments. The conclusions stressed the need to listen to children's and mothers' voice and taking into account their beliefs, and the impact of these beliefs on their experiences. Ultimately, such an understanding may provide a valuable conceptual lens for health and social care practitioners to use when working in family-centred, culturally congruent ways with parents.
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Publications and Presentations

The following work within this thesis has been presented elsewhere:

**Peer-reviewed abstracts**

**Poster presentation**
**Abbreviations**

AAC: Augmentative and Alternative Communication  
BD: Behavioural Disorders  
BTX A: Botulinum toxin type A  
CARF: Commission on Accreditation of Rehabilitation Facilities  
CNS: Central Nervous System  
CP: Cerebral Palsy  
CIMT: Constrained Induced Movement Therapy  
DRM: Disability Rights Movement  
DPT: Doctor of Physical Therapy Program  
FEID: Full-essentialist individual deficiency interpretation  
FREGC: Faculty of Health & Social Science Research Ethics and Governance Committee  
GMFCS: The Gross Motor Function Classification System  
GMFM: Gross Motor Function Measure  
HADS: The Hospital Anxiety and Depression Scale  
ICF: International Classification of Functioning  
ID: Intellectual Disabilities  
IQ: Intelligence Quotient  
IRB: Institutional Review Board  
KFMC: King Fahad Medical City  
KFSH&RC: King Faisal Specialist Hospital and Research Centre  
MOH: Ministry of Health  
NDT: Neurodevelopmental Therapy  
PEID: Part-Essentialist Individual Deficiency Interpretation  
PHC: Primary Health Care  
PhD: Doctor of Philosophy  
POD: Politics of Disablement Interpretation  
PPE: Pre-Service Physical Education  
SA: Saudi Arabia  
SCHS: The Saudi Commission for Health Specialities
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<td>SPTA</td>
<td>Saudi Physical Therapy Association</td>
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<tr>
<td>TLR</td>
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<td>UCP</td>
<td>The United Cerebral Palsy</td>
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<tr>
<td>UK</td>
<td>United Kingdom</td>
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<td>WHO</td>
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Thanks go to my friend and colleague Naif Al-Raddadi who read part of the thesis, for his time and constructive comments.

Finally, my immense thanks go to my parents, brothers and sisters who had showed me love and understanding.
Declaration

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree, and does not incorporate any material already submitted for a degree.

Signed

[Signature]

Dated
22/10/2014
Chapter 1: Thesis Rationale and Overview

1.1 Introduction

The purpose of this chapter was to contextualize this study by relating how the idea for the study was developed and outlining the factors that motivated it. Further, an indication of how the preliminary reading of the literature led to the refinement of initial ideas and clarification of the research problem was offered. In addition, the research questions were identified. The chapter concludes by delineating the issues covered in the remaining chapters of this thesis. The next section outlines my history of working with children with cerebral palsy, and explains why and how I came to undertake this research.

1.2 Personal and Professional Motivation for the Study

My personal and professional motivation to undertake this research has grown out of my experience of working with children with cerebral palsy (CP) over many years and also as a woman born and raised in Saudi Arabia, I have a good awareness about the challenges facing children with disability and their mothers as well.

Throughout my 17 years of work experience in the two of the biggest hospitals in Saudi Arabia/ Riyadh, working as a paediatric physiotherapist, I have observed the mothers’ perceptions and reactions to the medical term CP. I became particularly aware of their reaction on one particular occasion when the physiotherapy department announced that it was to hold a group therapy session for children with CP. We had previously identified from our list of children, the ones which could be included in this group. When we contacted one of the mothers to inform her about this group and its purpose, she declined to attend. She said that she believed that her child had a condition which resulted in developmental delay and that she did not have CP. She said that CP meant brain paralysis and this was not her child’s problem. I was surprised by this reaction and it caused me to monitor other mothers’
reactions when provided with the same diagnosis. It became clear that this was a typical reaction seen frequently in the daily routine of our paediatric physiotherapy clinic. The majority of the mothers, who come to the physiotherapy clinic without knowing their child’s diagnosis, had demonstrated strong negative feelings about the CP term.

In light of my clinical experience I chose to ask three Saudi mothers of children with CP, whether they would share their thoughts with me about the term ‘CP’ and what the diagnosis meant to them. The three mothers agreed to chat to me in a group about their feelings and also agreed to act as advisors to the study. Verbal consent was considered sufficient as the content of the discussion was of ideas which was undertaken in their native Arabic language. In a discussion with the hospital directorate, it was agreed that the subject of the advisory group was within my normal scope of practice and job description and therefore did not require additional ethical approval.

This advisory group endorsed that many mothers avoided the use of the term CP because their understanding of the term was that it meant brain paralysis. A direct translation of the term CP into Arabic language changes the meaning to brain paralysis. The mothers believed that the diagnosis of CP could only be made to children who were severely affected. They thought that children with CP had major problems with life activities such as language, mobility, learning, self-help, and independent living in addition to mental disorders. They had not acknowledged that CP could have a spectrum of effect from mild to severe

—My child is normal he only complains of delayed walking. Doctors have to think about the term before diagnosis. I think it is better to replace the term with delayed motor development. It is more acceptable in our society.” (Mother B)

These findings from the advisory group were illuminating and this discussion reinforced my decision to explore more widely the perception of the CP term in Saudi Arabia. This in turn raised questions for me about the implications of such labelling and how such perceptions could influence the mothers and children’s lives. I began to explore the literature to try and understand the social phenomena that I
was witnessing. A study undertaken in the United States, reported that mothers were more likely to feel embarrassed and guilty about their child’s disability if they themselves felt that people with disabilities were devalued and discriminated against in their community (Green 2003). Additionally, the same research group found that mothers who experienced significant amounts of stigma in relation to their child’s disability reported a higher burden of care for their child, were much less likely to interact with peers and were less likely to investigate age-matched interactions for their children (Green 2003).

Cross-cultural research clearly demonstrates that the cultural framing of disability impacts on the way we think about, speak about, and interact with disability. Our view of what disability is, what causes disability, what disability means in the context of participation, learning, working, relating to others, and what disability experience might be, holds tremendous power in shaping the trajectory of disabled children (Rosenthal and Roer-Strier 2001; Greenfield et al. 2003). Moreover, culture might influence how mothers think about their mothering roles with respect to their child with a disability (Danseco 1997; Santos and Mccollum 2007). It has been acknowledged in the literature that parents’ ideas about the nature and causes of their child’s disability, might influence how they think about the child (Danseco 1997), and different diagnoses of disability are likely to have different meanings to parents from different cultural backgrounds (Santos and Mccollum 2007).

It is acknowledged that to undertake best practice that healthcare professionals involved in rehabilitation understand and appreciate their clients’ values, beliefs and goals in order to be able to engage families in shared decision-making (Gibson et al. 2009; Panzarella 2009). Therefore, an understanding of cultural context and of what is normative within a particular cultural group is important to the practice. An understanding of mothers’ perceptions and beliefs about their child’s disabilities, and what influences these beliefs facilitates effective interactions between healthcare professionals, patients and their families. This ensures that health services are delivered in a culturally competent manner.

From what I had witnessed in my daily practice and with the advisory group, I was able to concur with the problem arising from the interpretation of the CP term by
Arabic language. In addition, I found a general lack of research regarding mothers’ and children’s experiences in the Arab world. Disabled children’s voices, what they have to say about their individual daily lives, have not been heard. Most research, exploring disability in Saudi, has been undertaken from a medical approach. Moreover, the literature also reported that parents and children frequently have different views, and highlighted the importance of listening to views of the children (Sloper and Lightfoot 2003). This study endeavours to bridge this gap by exploring the perceptions of children with CP and also the perceptions of their mothers, in order to understand their experience of disability and to explore the extent to which such perceptions influence their daily life. Overall, this study will give children with CP and their mothers an opportunity to express their views and experiences, something which has not happened in the Middle East before.

1.3 Research Question

What is the perception of the term –cerebral palsy” in Saudi Arabia?

1.4 Research Aims

The research question had the following aims:

- To explore the perception of the term CP with CP children and their mothers.
- To explore the implication of the meaning for mothers of children with CP.
- To explore the experiences of being a child with CP in Saudi Arabia

The thesis will be structured according to this research question and these aims.

1.5 Overview of Chapters

The thesis consists of ten chapters. A brief overview of the content and structure of this thesis is presented below.
Chapter 1- Thesis Rationale and Overview

This chapter introduces the nature of the research question under investigation and the reasons for the enquiry. In addition, it provides an overview of the thesis and the context in which it is set.

Chapter 2- Introduction

This chapter introduces the Kingdom of Saudi Arabia where the study has been conducted. It provides a description of the religious and cultural context as well as the Saudi family. This chapter also addresses the history and current position of healthcare system in Saudi Arabia, and discusses physiotherapy within Saudi Arabia.

Chapter 3- Concepts of Disability

This chapter presents the literature review that directly relates to the purpose and objectives of this study, including models of disability stigma and the current literature exploring the perception and experiences of mothers of children with disability. This chapter also addresses ecological model as a theoretical framework to inform the study. The final part explores disability within Saudi Arabia.

Chapter 4- Children and Childhood

This chapter considers theories of childhood and children's and the importance of doing research with children. It presents the available research evidence concerning children’s experiences and perceptions of disability. Finally, the chapter address and the child's welfare in Saudi Arabia.

Chapter 5- Overview of Cerebral Palsy

This chapter provides background information about children with CP. It address the medical concept of CP including etiology, causes and risk factors of CP, classification, clinical features and associated problems. It describes information about the condition and its effects on functioning, mobility, and general health status. Finally, the chapter illustrates the trends in the management of cerebral palsy.
Chapter 6- Research Methodology

This chapter address the methodology of critical ethnography. It introduces the reader to aspects of critical theory and ethnography, the epistemological and ontological issues around qualitative research to provide a rationale for selecting a critical ethnographic approach. Finally, the chapter discusses the measures taken to ensure the trustworthiness of this research study.

Chapter 7 – Research Method

This chapter present the research methods used in this study including the setting of the study, and sampling techniques. It also explains the process of data collection including techniques and procedures used for collecting data. Additionally it addresses the ethical consideration relevant to the study. Final part addresses the Carspecken's (1996) five stages of critical ethnography which guided the analysis.

Chapter 8- Mothers Findings

This chapter presents the findings of the mother's focus group and interviews including the major themes and sub-themes that emerged in the context of the analysis.

Chapter 9- Children Findings

This chapter presents the children's views including the major themes and sub-themes that emerged in the context of the analysis.

Chapter 10- Discussion of Findings

This chapter discusses the findings in relation to the ecological frame work and the existing literature and previous research.
Chapter 11- Conclusion and Clinical Implications

This chapter summarizes the key findings of the mother’s focus group and children interviews, the contribution to knowledge, the implication to practice and ends with study limitations and suggested recommendations for future research.

Chapter 12- Reflection

This chapter presents the reflection on the study process related to research, practice and theory.
Chapter 2: Introduction and Background of Saudi Arabia

2.1 Introduction

This chapter presents and reviews the relevant literature in support of conducting a study in the Kingdom of Saudi Arabia. It begins by giving an overview of Saudi Arabia, describes the Religious and cultural context, as well as the Saudi family. Then, it also provides background information on Saudi Arabian health care system, and introduces the physiotherapy profession. Finally, it provides a brief summary of the chapter.

The importance of this chapter is to provide the reader with background knowledge about the social and cultural aspects that may influence children and their mothers' experiences and perception. It is intended as an aid, particularly for those who are unfamiliar with Saudi Arabia's history, land, people and social welfare, health and educational system, providing a contrast between the reader's frame of reference and that of the present study.

2.2 Overview of Saudi Arabia

The Kingdom of Saudi Arabia was established as a country in 1932. Its name, 'Kingdom of Saudi Arabia', derived from the family name of the first king, Abdualaziz Ibn Saud, after his effort to unite the Arabian Desert tribes and the country (Long 2005).

Saudi Arabia is one of the largest countries in Asia and the largest country of Arabian Peninsula. It is located in the heart of the Arabian Peninsula and occupies around four-fifths of the Arabian Peninsula. Saudi Arabia lies to the extreme southwest of Asia, on its northern border lies Kuwait, Iraq and Jordan, and to the south are Yemen and Oman. It is bordered on the east by the Arabian Gulf, Qatar and United Arab Emirates and on the west by the Red Sea (Almunajjed 1997).
The territory of Saudi Arabia is divided into thirteen provinces, and each province is headed by a royal family member (Central Department of Statistics and Information 2012). Riyadh is the capital city of the kingdom, and Arabic is the official language.

The total Saudi population as of the April 2010 census increased to 27,136,977 million of which about 8,429,401 million are non-nationals expatriate (Saudi Gazette 2010). Saudi Arabia's population is characterized by rapid growth and a large cohort of youths. The ethnicity of the Saudi population is primarily Arab; however, other ethnicities migrated over the years to the Hijaz region, especially during the pilgrimage seasons - these groups come mainly from Turkey, Persia, Africa, and South Asia (Demographics of Saudi Arabia. 2013).

Figure 2.1- Map of the Kingdom of Saudi Arabia
Moreover, Saudi Arabia is at the heart of all Muslims' affections because within its boundaries are the most important and respected places for each Muslim; namely, the two holy mosques of Mecca and Medina. Given that Saudi Arabia is considered the birthplace of the Islamic religion, both the government and society adhere to strict and conservative interpretation of Islamic Law, also known as Shari'a. Under Sharia law, certain rights are applied to all people, such as life, dignity and education (The World Factbook 2010).

The Kingdom of Saudi Arabia is a theocratic monarchy. It is ruled by a royal family, which rules according to the Quran’s teachings of Sharia based on Islamic religious law (The World Factbook 2010).

The Council of Ministers, also called the Cabinet, advises the King and facilitates the country’s development. It represents 22 different government ministries and is presided over each week by the King or his deputy. The Cabinet is responsible for drafting and overseeing implementation of the internal, external, financial, economic, education and defence policies, as well as the general affairs of the State (Council of Ministers of Saudi Arabia 2013).

The “Consultative Assembly of Saudi Arabia” represents one of the ruling methods in the country. It is the formal advisory body of Saudi Arabia, and it cannot pass or enforce laws, a power reserved for the King. The Consultative Assembly has limited powers in government, including the power to propose laws to the King (Consultative Assembly of Saudi Arabia 2013). The Consultative Assembly is permitted to propose draft laws and forward them to the King, but only the King has the power to pass or enforce them. The Assembly does, however, have the power to interpret laws, as well as examine annual reports referred to it by state ministries and agencies. It can also advise the King on policies he submits to, along with international treaties and economic plans. The Assembly is also authorized to review the country's annual budget, and call in ministers for questioning (Consultative Assembly of Saudi Arabia 2013). The influence of the Assembly in its present form comes from its responsibility for the Kingdom's five-year development plans, from which the annual budgets are derived, its ability to summon government officials for
questioning, and its role as policy debate forum (Consultative Assembly of Saudi Arabia 2013).

The Council is situated in Riyadh and consists of 150 members, all of whom are appointed by the King for a four-year term of office. In January 2013, King Abdullah issued two royal decrees, granting women thirty seats on the council, and stating that women must always hold at least a fifth of the seats on the council. According to the decrees, the female council members must be "committed to Islamic Shariah disciplines without any violations" and be "restrained by the religious veil." The decrees also states that female council members would enter the council building from special gates, sit in seats reserved for women and pray in special worshipping places. Earlier, officials said that a screen will separate genders and an internal communications network will allow men and women to communicate. Therefore, women first joined the council in 2013, occupying thirty seats. Furthermore, that year three women were named as deputy chairpersons of three committees, including the human rights and petitions committee, the information and cultural committee, and the health affairs and environment committee (Consultative Assembly of Saudi Arabia 2013).

Saudi Arabia is currently experiencing social change at an unprecedented rate, driven by oil wealth and the government’s commitment to modernization. In the last few decades, the Kingdom has spent billions of dollars on social, physical and economic infrastructure, including modern education, transportation, communications, health care and sanitation. Today, the majority of Saudis live in the cities; agriculture barely features as an economic activity. Although Saudi Arabia has seen dramatic developments in the last few decades, the authorities have always attempted to conserve the traditions and culture of the country.

2.3 Religious and Cultural Context in Saudi Arabia

Culture refers to the beliefs, values, meanings and actions that shape the lives of a collective of people, influencing the ways people think, live and act (Iwama 2005; Hammell 2006). These beliefs, values and ways of understanding are socially
constructed and specific to the culture in which they are found (Burr 2003). Culture shapes individuals’ notions of health, their understanding and perception of illness, their beliefs about health risks, and their expectations of the doctor–patient relationship (Ware and Kleinman 1992; Narayan 2002; Mandell and Novak 2005). Furthermore, cultural environment affects the way in which people with disabilities perceive their disability, or are perceived by others and also influence how parents think about their parenting roles with respect to their child with a disability (Danseco 1997; Santos and Mccollum 2007).

The research question of this study is "What is the perception of the term 'cerebral palsy' in Saudi Arabia?" It is therefore important to explore the diverse aspects of culture that contribute to define the Saudi family, and its adaptation to disability. Culture in Saudi Arabia is embedded by Islam, However, economic status, level of education and environmental factors are also responsible for shaping the culture (Al-Shahri 2002; Buckman 2011). Gender is an important factor which contributes to conceptualization of Saudi Arabian culture, and Islam provides equal rights for male and female children, while regulating their relations (Al-Azhar University, 2005). Saudi Arabian girls share the general rights in the society, such as rights related to care and protection during early childhood, health and education. However, segregation between men and women is a very visible feature of the Saudi Arabian society, as men and women seldom interact across the gender divide outside the domestic space of families (Almunajjed 1997). For example, social interaction takes place in groups that are gender-and age-specific. It is a requirement for women to cover themselves up in public. However, within women-only occasions and events, women do not wear scarves on their heads. In fact, they display modern habits and dress, wearing make-up, and expensive or fashionable clothing (Almunajjed 1997).

As a fundamental doctrine in the Islamic faith, people believe in predestination and attribute the occurrence of disease to the will of God (Allah). They do not generally perceive illness as a form of punishment but rather as a way of atonement for one’s sins. A disability or sickness is considered to be a test from God (Allah) to determine whether the individual has patience, believes in their destiny and thanks God for whatever is sent to him/her (Alshaia 1997). It is believed that the person
who is patient and endures suffering will be rewarded in the hereafter. This kind of belief may pose some problems for healthcare providers if individuals do not adopt an active role in promoting their own health and wellbeing. Muslims are instructed to show patience, and they are also encouraged to seek care and treatment during illness (Rassool 2000).

In Saudi Arabia, the “Evil Eye” concept is one of the traditional ill health attributions. Many people believe the evil eye can cause impairment, disability, sterility, childbirth problems, deficient breast milk, domestic problems, accidents, illnesses and unemployment. The evil eye is also thought to affect children, adults, livestock and people's possessions. People who are young, wealthy and particularly handsome are considered more at risk (Al-Sughayir 1996). Spiritual healing methods are widely practiced by Saudis for the whole spectrum of diseases, with particular emphasis on conditions for which no curative medicinal treatment is known (Al-Shahri 2002). The common spiritual healing practices among Saudis are the ones advised according to the teachings in the Holy Qur'an and (or) Sunnah. These include the healing of conditions of those who are possessed by Jinn (evil spirit) (Al-Shahri 2002), mal-effects of evil eye, and poisonous stings (Khan 1994 cited by Al-Shahri, 2002). The main spiritual modality of treatment is the recitation of verses of the Holy Qur'an and specific sayings of the Prophet Mohammad (Peace Be Upon Him). Zamzam water (obtained from the Zamzam well in the Holy Mosque in Makkah), honey, and black cumin (Nigella seeds) are considered as healing agents (Al-Shahri 2002).

2.4 The Saudi Family

To understand the Saudi culture, I will address the structure and function of the Saudi family in this section. The cultural environment of the family fundamentally influences the processes of adaptation to the disability (Groce and Zola 1993; McCubbin et al. 1993). These processes of family life are the way in which families give "meaning" to having a child with a disability and they play a fundamental role in shaping the family's responses to medical care (McCubbin et al. 1993).
The traditional Saudi family is based on an extended family unit, which consists of the husband, wife, their children, and their married children with their spouses and grandchildren (Al-Saif 1991). Family members in Saudi Arabia expect great loyalty from each other and accept familial obligations because this provides them with harmony and personal identity (Al-Saif 1991). Therefore, a disabled person is cared for by their families, rather than by an institution. However, many family members do not have the knowledge or expertise to provide adequate or appropriate care to the disabled person even though this kind of responsibility is part of Islamic laws and traditions.

A close relationship exists between families and relatives, and much effort is made to maintain stable relationships. Family affairs are considered confidential and not for discussion with non-family members. Family honour is critical, and determines the basis of male-female relations in Saudi Arabia. The male's dignity and pride depends upon being responsible for his kinswomen economically, legally, and morally (Al-hazzaa 1993). Traditional gender roles in Saudi society share a number of common characteristics with other traditional societies, the most notable of which is that men’s roles are outside the home as family providers, protectors, and managers and women’s roles are in the home. Men are predominant outside the home in business and public affairs, and women are to a large degree predominant within the home, particularly in parental decision making (Long 2005). Gender roles, however, are changing with rapid modernization. Nowadays, there appears to be more male acceptance of expanding women's participation outside the home in professional careers, which is occurring in part for economic reasons. At the same time, there is a strong male resistance to playing a more active role in managing the home and child rearing (Long 2005).

Marriage is often desirable among Saudi Arabian girls, as they wish to escape parental control and supervision. For single girls, marriage is a way to freedom, a greater social life, and control over their own homes. The availability of expensive domestic maids and drivers in most homes enables many women to continue their education or go out to their work (Al-hazzaa 1993).

The cost of getting married is very high and it is very difficult for a person to marry without the support of parents or relatives. Pre-arranged marriages are common, and are initiated when the mother of a man visits a family to meet the prospective wife.
The mother then informs her son about the woman, and he decides whether he likes what he hears. Traditionally, marriage was between paternal first cousins or other patrilineal related kin. It was customary for potential spouses not to meet before the wedding night and marriages had to be arranged by fathers, mothers and other relatives. However, these practices are also changing, and the tendency is moving away from close-cousin marriages and for the couple to communicate with each other before the wedding. Parents still arrange marriages, but they are more likely to manage them indirectly.

A Saudi Arabian family is generally relatively large compared with a typical Western family. Furthermore, the growth rate of the population in the Kingdom is very fast due to the socio-economy changes that are taking place. As a result of high population growth rates, average Saudi Arabian family size reached 7 persons in 1996; varying between 7.5 in rural areas and 6.8 in urban areas. Thus, Saudi Arabian families are in need of economic support through provision of job opportunities, increasing income, improving social care and services, with particular focus in the age structure of the family that is characterized by the dominance of young age groups, such as children and youth in the critical age of growth and dependency (The Eighth Development Plan 2005 – 2009, n.d. p 305).

Saudi Arabian families have evolved as a result of socio-economic changes since many Saudis have moved from rural villages to larger urban areas because of job opportunities and expectations of a better life. This has led to changes in the family structure as sons and daughters may need to move away and thus the family units become smaller. This rapid urbanisation has brought with it changes in the way of living and a shift in values and norms. Comparing current children with previous generations, children today are living in a different society with regard to its material culture. However, this change in the family structure has not affected the families' role regarding their children and the role of sons and daughters towards their parents as Saudi Arabian cultural values. Moreover, this requires the provision of mutual support for relatives and elderly parents, and this persists in Saudi Arabian families. For instance, it is considered dishonourable in Saudi Arabian culture to place an elderly parent in a nursing home; it is also the duty of the family to look after their divorced or widowed daughters or sisters (Al Rubiyea 2010).
In summary, the extended family, as the basic structural unit of Saudi society, continues to be a major influence on all aspects of Saudi social, political and economic life despite the centrifugal forces of modernization eroding its cohesion. Given the furious rate of social change that is occurring, the remarkable thing about the traditional society is that the family role toward children or parents or the family duties and ties has not been affected.

2.5 Healthcare System in Saudi Arabia

The healthcare system in Saudi Arabia is classified as a national health care system in which the government provides health care services through a number of government agencies. Health services in Saudi Arabia are provided through three main sectors: the Ministry of Health (MOH) network of hospitals and primary healthcare centres that are distributed throughout the country, other governmental institutions, and the private sector (Albejaidi 2010).

The MOH is the largest provider of healthcare services in the Kingdom, providing 59.5% of the total health services in Saudi Arabia (Almalki et al. 2011). Although the MOH is charged with the healthcare of the entire population, other governmental and private facilities are also important health care providers and provide 19.3% and 21.2% of the health services, respectively (Walston et al. 2008; Almalki et al. 2011).

The MOH also provides 2,037 Primary Health Care (PHC) services through a network of health care centres. The referral system provides care for all members of society from the level of general practitioners at health centres to advanced technology specialist services through 220 general and specialist hospitals (Almalki et al. 2011). The MOH is considered to be the leading government agency responsible for the management, planning, financing and regulation of the health care sector.

Other governmental sector healthcare providers include facilities that are highly respected, and generally, considered better quality. These include facilities funded by the Ministry of Defence and Aviation Medical Services, Ministry of Interior
Medical Services, National Guard Medical Health Affairs, University hospitals, King Faisal Specialist Hospital and Research Centre (KFSH&RC), and The Royal Commission for Jubail and Yanbu provides health facilities for employees and residents at the two industrial cities (Jubail and Yanbu). The second largest healthcare provider, other than the MOH, is the Medical Services Department of the Ministry of Defence (Figure 2.2) (Walston et al. 2008; Almalki et al. 2011).

Figure 2.2- Current structure of the health care sectors in Saudi Arabia (Almalki et al. 2011)

The private healthcare sector, including hospitals and clinics, continues to grow due to the increase in demand for health services where individuals can purchase quick and high quality care (Barrage et al. 2007). The private sector has grown rapidly over the past several years and expanded its services, especially in the large cities of Saudi Arabia, such as Riyadh and Jeddah.
In 1971 there were only 18 private hospitals; however, by 1996 this number had grown to 75 and by 2005 to 113. This accounts for approximately 21% of all hospital beds. The private sector has been the primary provision for foreign workers until very recently. However, the MOH has devised a plan to alleviate pressure on public hospitals and to ensure that all workers in companies have access to health provision. Therefore, in the 1980s, the MOH ordered all companies to provide compulsory health insurance for all their expatriate workers, which resulted in the companies having to pay for an extensive package of services according to their choice of private hospitals (Barrage et al. 2007).

<table>
<thead>
<tr>
<th>Saudi Arabia</th>
<th>Numbers</th>
</tr>
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<tbody>
<tr>
<td>Population</td>
<td>28,376,355</td>
</tr>
<tr>
<td>Number of hospitals</td>
<td>415</td>
</tr>
<tr>
<td>Number of beds</td>
<td>58,696</td>
</tr>
<tr>
<td>Hospitals affiliated to MOH</td>
<td>251</td>
</tr>
<tr>
<td>Number of beds in hospitals affiliated to MOH</td>
<td>34,450*</td>
</tr>
</tbody>
</table>

MOH - Ministry of Health, *10,948 beds in other governmental sectors

Table 2.1 Population, number of hospitals, and available beds in the Kingdom of Saudi Arabia (Al-Jadid 2013).

Another unique aspect of healthcare in Saudi Arabia is that every year, the country serves more than 5 million pilgrims and visitors to the Holy Mosque in Makkah. The government provides free health services to pilgrims through the Ministry of Health facilities. In 2005, in the month of Ramadan, nearly 3.4 million pilgrims came to Makkah to perform Omrah (religious activities). According to the Saudi Arabian authorities, more than 250,000 cases of pilgrims were treated in the MOH facilities that year. MOH assigned 22 hospitals and 165 primary care centres to serve pilgrims during the Hajj pilgrimage activities with more than 9,600 personnel, including
physicians, nurses and allied health personnel, engaged to work in these health centres (Walston et al. 2008).

A physiotherapy department is available in each hospital. The nature of the department, its facilities and provision will vary according to the hospitals resources. Some of Riyadh hospitals have a paediatric physiotherapy clinic, but not all. Unlike United Kingdom (UK) and western countries, patients/clients need referral from physician to access physiotherapy clinic.

Healthcare is currently free of charge in Saudi Arabia to all Saudi Arabian citizens and expatriates working in the public sector. It is funded primarily through the Ministry of Health and augmented by other governmental health facilities. The government also requires that expatriates working in the private sectors have some level of healthcare coverage paid by their employers (Walston et al. 2008).

2.6 Physiotherapy Education and Regulations in Saudi Arabia

The Ministry of Higher Education established the College of Applied Medical Sciences section of rehabilitation science department in 1979 to meet the need in the Kingdom of Saudi Arabia for skilled health care professionals. Until very recently, the college of Applied Medical Sciences at King Saud University was the only physiotherapy collage in the kingdom of Saudi Arabia (Rehabilitation Science Department 2009). Currently, Saudi Arabia has 19 schools of physiotherapy, which offer physiotherapy programs at a Bachelor degree level. There is one school that offers a masters level, and two of them offer Doctor of Physical Therapy Program (DPT). The length of Bachelor level program is typically 5 years including one internship year.

Like most other countries, all physiotherapists must receive a graduate degree from an accredited physiotherapy program before taking the national licensure examination that allows them to practice. The Saudi Commission for Health Specialities (SCHS) is the corporate body of the scientific commission, which is licensed to provide evaluation for all holders of health certificates prior to
professional classification and practice within the Kingdom of Saudi Arabia (Saudi Commission for Health Specialties 2014).

According to SCHS, physiotherapists who obtain a Bachelor degree are classified as a specialist, while physiotherapists with a Master of Science and 2 years of experience are classified as senior specialists. Physiotherapists with a PhD and 3 years of clinical experience are recognized as Consultant physiotherapists (Saudi Commission for Health Specialties 2009).

Although SCHS is the accrediting body for physiotherapy profession, each hospital in Saudi Arabia has its own accreditation criteria, for example King Fahad Medical city (where the study has been conducted) credentialed physiotherapist as physiotherapist II for newly graduate physiotherapist, physiotherapist I for physiotherapist with 5 years of experience including 2 years of specialist experience or hold a Master degree with 2 years of experience, and senior physiotherapist for physiotherapist with 7 years of experience including 2 years of specialist experience or hold a Master degree with 4 years of experience.

Saudi Physical Therapy Association (SPTA) is the official non-profit association created to develop the profession of physiotherapy in Saudi Arabia and for skill development of physiotherapy professionals. The agreement to establish the Saudi Arabian society for Physiotherapy was issued by the King Saud University's council in 1981; however, the actual activity of the association did not start until 2001 by forming a preparatory committee whose task was to establish the foundation for the association. The association seeks to achieve many objectives through its various activities, most importantly to upgrade the physiotherapy services in the Kingdom of Saudi Arabia, promote scientific research in the various physiotherapy areas, upgrade the scientific and practical efficiency of the physiotherapists, collaborate between workers in the local, Arab and International level, and to spread awareness and concern to maintain health in the community (Saudi Physical Therapy Association).
2.7 Summary

This chapter has provided a brief overview of Saudi Arabia and how Islam is socially integrated with Saudi Arabian culture. It has also described the typical Saudi Arabian family, considered the health care system, as well as its challenges and demands. Then, detailed the physiotherapy educational provisions in Saudi Arabia.

The next chapter presents the literature of disability research and the theoretical framework of the research.
Chapter 3: Concepts of Disability

3.1 Introduction

This chapter reviews the relevant literature to the study. It is organised into five sections. The first section reviews the relevant literature on disability, including the models of disability. The second section discusses the ecological model as a theoretical framework informing the study. The third section discusses the gaps in the literature relevant to the perception and experiences of mothers of children with disability. The fourth section discusses the stigma of disability. And the last section discusses disability in Saudi Arabia as well as reviewing the literature of disability research in Saudi Arabia.

Since there is no Saudi literature dealing with this subject and there is no socio-political movement representing disabled people in Saudi Arabia, I resorted to western literature on disability movements and the development of disability theories.

3.2 Understanding Disability

Disability is often defined by individuals and society through comparisons or references to socially constructed notions of "normalcy". This notion of "normalcy" is largely dependent on the frame of reference within which abilities and disabilities are viewed (Hetzroni and Harris 1996). According to the World Health Organization (WHO), the term "disability” is an overarching term that describes activity limitations, impairments and participation restrictions. An impairment is considered to be a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action, while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus, disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she
lives (World Health Organization 2011). Consequently, whilst disability affects individuals and their families across the world, the frames of reference within which disabilities are perceived can be shaped by many mediating factors, including social and cultural influences, traditional practices and personal experiences (Brown 1997; Brown 2002; Barnes 2003; Bickenbach 2009). The extent of these influences can also impact the way health services are approached and understood, thereby affecting health-seeking and health-promoting behaviours (Oliver 2009; Padela et al. 2012).

3.2.1 Model of Disability

Although the majority of disability research has been conducted within the context of either social or medical models, different models have been proposed to explain the concepts of disability. Models of disability provide a framework for understanding the way in which children with CP and their mothers perceive and experience disability. They also provide frameworks for understanding the causes of disability and by implication, the means to ameliorate them” (Bricout et al. 2004).

In this section, the literature concerning the medical and social models of disability and the International Classification of Functioning (ICF) will be briefly outlined.

3.2.2 The Medical Model of Disability

The medical model of disability perceives disability as the result of some physiological impairment due to damage or a disease process, leading to a view of the person having a 'condition' which requires 'treatment' (Oliver 2009). The medical model of disability (Figure 3.1) focuses on the individual's impairment as being the barrier to them engaging fully with society, and it is through change within the individual that these barriers will be removed (Shakespeare and Watson 2002). The main focus of the model is on medical intervention and the rehabilitation of disabled people, such as operating to reduce the need for a wheelchair (Oliver 2009). Within this model, health care is seen as restoring the person's 'normal functioning', which implies to many that disabled people are abnormal (McLean and Williamson 2007).
The medical model has been commonly regarded, by the Disability Rights Movement (DRM), as an inaccurate interpretation of disability forming the basis of oppressive and exploitative relationships between non-disabled and disabled people. The argument is that focusing on individual medical conditions as the causes of disability, the medical model first, incorrectly defines disability as a fixed condition related to the severity of a medical impairment. Second, it also incorrectly assumes that it is this medical condition, often defined as ‘handicap’, which inevitably causes ‘dependency’ between disabled and non-disabled people (Smith 2009). So, according to Barnes and Mercer (2010), the medical model links the term ‘handicapped’ with ‘individually based functional limitations’ which, in turn, falsely implies that: ‘The impairment is permanent and that (the handicapped) will almost certainly remain dependent throughout their lives.’ (Barnes and Mercer 2010)

![Figure 3.1 Medical Model of disability (Adopted from Harris and Enfield 2003)](image-url)
3.2.3 The Social Model of Disability

Criticism of the medical model led many disabled people to develop a social model of disability aimed to challenge some of the prevailing views of disability and negative social associations put forward by the medical model (Oliver 2009). The social model of disability (Figure 3.2) offers an alternative paradigm for understanding disability by identifying causes of disability within social and political domains (Smith 2009). Therefore, the experience of disability is not reduced to a fixed medical state relating to the severity of a particular medical impairment, but rather is an experience that is dependent upon how society is politically and socially organised and structured in relation to particular medical conditions (Smith 2009). From this vantage point, the focus for the DRM is on the ‘politics of disablement’ where citizenship, inclusion and the problems of accessibility and discriminatory barriers to participation are seen as central to the struggle of ‘being disabled’ (Oliver 2009); that is, rather than focusing on individually based functional limitations which require treatment, adjustment or ‘cure’, as defined by the medical model.

Figure 3.2 The Social Model of disability (Adopted from Harris and Enfield 2003)
Although the model challenges the society role in disability, and provides disabled people with an identity, it has moved away from being impairment-focused and allows them to deny impairment. Thus, they have become attached to the social model and incorporated it into their identity (Shakespeare 2006). The model assumes that individuals will identify themselves as _disabled_, and does not account for disabled people wanting to identify themselves by other dimensions, such as gender, race or sexuality (Shakespeare and Watson 2002). The counter argument points out that there is no evidence that the model could not incorporate these factors (Oliver 2004). By imposing such restricted thinking however, this model, in turn, is recreating the errors of the medical model in defining people in accordance with their impairment (Shakespeare and Watson 2002).

The most widely discussed limitation of the social model is the lack of acknowledgement given to impairments, such as functional limitation or pain. It sees disabled people as being disabled by society only, and not by society and their body (Barnes 1998; Shakespeare and Watson 2002). Without looking at the role of impairment, it is not possible to understand the complexity of disabled people's lives (Shakespeare 2006).

Moreover, the model does not represent the experience of all disabled people, such as those who have a learning impairment, or a mental _illness_ (Shakespeare 2006; Thomas 1999). Thomas (1999) argued that the experience of disabled people is not straightforward, due to social differences such as gender, race, sexuality, age and social class, as well as the presence of impairment which results in disabled people sometimes experiencing difficulties without external barriers (Thomas 1999).

Disability is a highly complex issue; it is multi-dimensional and it cuts across the range of political, social and cultural experiences. Whilst the social model provides a valuable political tool, it only offers a relatively small window through which to examine the lives of disabled children and, by focusing solely on the material, its analysis is perhaps too one-dimensional (Watson 2012). Disabled children are not a homogenous group and neither are they a cohesive collective with a common identity and interests (Corker et al. 1999). There are many particular subgroups, all of which experience disability in different ways. For example, ethnicity and ethnic
background affect the experience of childhood disability (Hussain et al. 2002). Emerson and Hatton (2007) have pointed to the impact of social class on the experience of disability in childhood. Their research suggests that the increased rates of mental health problems found in children and adolescents with a learning disability are the result of poverty and living in areas of high social deprivation. Gender may also impact on the experience of childhood disability (Emerson 2003). Disabled children living in the Global South also experience disability differently to those in the Global North (Filmer 2008; World Health Organization 2011).

Furthermore, how impairments impact on individual children’s lives is another area that has been neglected. Disabled children have different needs and different experiences; for example, a child who has CP differs from a child with a progressive condition (Shakespeare and Watson 2010). As Thomas (1999) argues, impairments can, in themselves, be limiting. These limitations may make it impossible for the children to participate fully in the community or in an activity, either because they have a narrow margin of health or the technology does not exist that would enable them to participate.

An important motivation for this study was for me to develop a more holistic understanding of the mothers’ and their children’s experiences of being disabled within the Saudi culture. Whilst it is acknowledged that the social model of disability is becoming widely accepted in the West and in academic circles, it is largely unheard of within the Middle East. Some cautious Arab researchers argue that the social model may not be directly relevant to the daily life of grass-roots disabled Arab people, and the model’s contribution may be limited to the provision of an insightful view towards a conceptual understanding of disability, in those countries (Nagata 2008).

3.2.4 Reinterpretation of the Medical and Social Model

Very recently, Smith (2009) revisited the interpretation of the medical and social model in an effort to clarify the different types of claims that can be made by DRM.
Smith argued that each interpretation has distinct implications for the way disabled people are viewed and treated.

One objection by the DRM, to the medical model, is that it is based on what is seen as an essentialist notion of disability (Swain et al. 2003). This associates being disabled with fixed and essential characteristics, seen via the perspective of non-disabled people and experts, that inevitably preludes a life of personal loss or tragedy. Smith (2009) calls this interpretation of the medical model the ‘full essentialist individual deficiency’ interpretation (FEID). The main point is that policies and practices based on FEID render disabled people as passive and powerless targets of intervention through non-disabled expertise. For the DRM, this reduces the person and his or her experience to an essentially ‘abnormal’ and ‘lesser than’ medical condition (Smith 2009). In respect to policy and practice, the FEID is reflected in legislation throughout the industrialised world explicitly defining people with impairments as medically ‘deficient’, ‘sub-normal’ and the like. Consequently, policies of segregation and medical treatment have been legitimated where disabled people, being seen as essentially deficient, are categorised as unable to function ‘normally’ and therefore requiring separated and ‘special’ care (Hevey 1992 cited by Smith 2009).

The second interpretation is the ‘part-essentialist individual deficiency interpretation’ (PEID). This assumes an impaired person is able to participate, at least to some extent, in social activities despite their individual medical deficiencies, and as long as the social and physical environment is changed to accommodate them. In other words, PEID still assumes that essential differences between ‘the disabled’ and ‘non-disabled’ exist, but that these differences do not mean that a disabled person cannot ‘function normally’, at least in certain social contexts (Smith 2009). The PEID, which combines or synthesises elements of the medical and social model of disability, can be found in various policies and practices and is used implicitly by the World Health Organisation in its Second International Classification of Functioning, Disability and Health (World Health Organisation 2002).

However, the compromise between the two interpretations is still seen as inadequate by many within the DRM. So, although the second, more socially-minded,
interpretation has moved away from the FEID understanding of individual deficiency, it still explicitly relies on a medicalised understanding of disability and so cannot avoid an essentialist interpretation of normality. Therefore, disabled people are still defined as ‘problematic’ because they are unable to conform to standards of normality which, in turn, are standards that are associated with what is seen as ‘ideal’ or ‘best’ (Smith 2009).

On the other hand, the two interpretations for the social model are ‘politics of disablement’ interpretation (POD) and social construction of disablement interpretation (SCOD). POD interpretation is directed towards changing the social and political environment. In other words, this interpretation offers a structural, as distinct from an individual, account of disability, in effect bracketing the personal experience of disability, other than that which an impaired person might experience, in relation to the social and political environment. Smith (2009) argued that the POD interpretation is radically challenging the two medical model interpretations, and adheres to the same essentialist myth of ‘ordinary’ or ‘normal living’, because it, too, relies on fixed assumptions concerning the ‘normal’ and ‘abnormal’ as related to ‘ideal’ and ‘non-ideal’ states of being. The POD interpretation often portrays disabled people as looking forward to, and struggling for, a future where they can participate in the same ideal and normal state as ‘the non-disabled’ already are, supposedly, enjoying. The second interpretation is SCOD, which means disability is caused by the way impairments are defined and associated with characteristics that are necessarily assumed to have a negative impact on personal identity, development and fulfilment. The SCOD interpretation of disability unashamedly allows and encourages a disabled person to have a positive attitude to himself, his identity and his impairment by, in effect, conceptualising the latter as a positive part of that person’s identity. Table 3.1 summarises the four interpretations of the medical and social models thus far outlined.
Table 3.1 Interpretations of the medical and social models (Smith 2009)

Although medical and social models have their contribution to the understanding of disability, no one model on its own can explain disability (Shakespeare 2006). The social model neglects the importance of impairment for many people with disabilities by considering that, in reality, it is difficult to distinguish between disability, impairment and social barriers. In addition, different kinds of disability
have different barriers (Shakespeare 2006; Watson 2012), while the medical model fails to reflect the reality of the experiences of people with disabilities (Barnes and Mercer 2010). Therefore, conducting disability research requires a balanced input from both models. An ecological model of disability, as will be discussed later in this chapter, is considered as a most appropriate theoretical framework for the study. This model was derived from developmental psychology to account for the synergistic influence of the individual's characteristics and the environment disability over the course of time; a 'process-person-context' model (Bronfenbrenner 1989; 1992 & 2005).

3.2.5 International Classification of Functioning (ICF)

Extremes of the medical and social models of disability exaggerate, respectively, the contributions of intrinsic impairment and environment to the disadvantage experienced by disabled people (Forsyth et al. 2007). In 2001, the World Health Organisation published the International Classification of Functioning (ICF), Disability and Health, indicating that the classification encompassed a number of concepts or words in common usage (World Health Organisation 2002).

As noted by Ravindran and Myers (2012), the ICF sees disability as a mainstream and universal human experience, and asserts that every human being experiences some degree of disability as a result of natural decrements in health that occur over the course of a lifespan. By shifting the focus from cause to consequence, the ICF places all health conditions on an equal footing, allowing them to be compared using a common metric ruler of health and disability” (World Health Organisation 2002).

Participation is defined in the ICF as ‘involvement in life situations‘ and replaces the concept of ‘handicap‘ (World Health Organisation 2002). For children, this includes domains of learning and applying knowledge, communication, home life, school life, social life, relationships and leisure and recreation (Morris 2009). Participation is recognised to be determined by both intrinsic impairment and environmental or contextual factors. Environmental factors are the physical, social and attitudinal environment in which people live and conduct their lives‘. By including contextual
factors, the ICF allows us to appreciate the impact of the cultural context on a person’s functioning. Hall and Hill (1996) observe that the extent to which a disability imposes a “handicap” for an individual is determined not only by the severity of the condition but also by family attitudes, financial resources, adaptations in the physical environment, legislation to support individuals with disability and the prejudice (or acceptance) of society.

Personal factors include preferences, personal choice, past experience and social background. These personal factors are not, however, classified, and it is unclear why the ICF regards them as context rather than factors intrinsic to the person, such as personality, temperament or impairments (Colver 2006).

Figure 3.3 Example of the Application of ICF Model (World Health Organisation 2002)
3.3 Theoretical Framework: Ecology Theory

This study focused on understanding the meaning of the term CP from the children with CP and their mothers, thus Bronfenbrenner's (1989, 1992 & 2005) ecological systems theory will be used as a theoretical framework of the study to help facilitate the interpretation of the data.

Bronfenbrenner's ecological systems theory is a socio-cultural view of human development that focuses on the mechanism of interactions between a person's attributes and his or her environment (Bronfenbrenner 1989 & 1992; Adamsons et al. 2007). This theory acknowledges that child development does not appear in isolation, but is shaped in relation to the child's parents, friends, home, school, community and society. Therefore, examining personal characteristics or contextual characteristics alone will not provide an explanation for the mechanism of human development (Bronfenbrenner 1989). Moreover, Bronfenbrenner's theory has recently evolved to “Bio-ecological Theory of Human Development” for emphasising the child’s biology, a primary environment fuelling his or her environment (Bronfenbrenner 2005;Bronfenbrenner and Morris 2006).

The ecological perspective argues that human development is shaped by the interactions between persons and contexts (Bronfenbrenner 2005). Further, it encompasses four features: Process, Person, Contexts and Time (PPCT Model) (Bronfenbrenner 2005; Bronfenbrenner and Morris 2006).

The first tenet is process. Process is the dynamic interaction between an active person and his/her environment. It is particularly important as “the primary engine of development” (Bronfenbrenner and Morris 2006, p.996). The second tenet of Bronfenbrenner's theory, person, refers to the individual and his or her characteristics (for example sex, age and health) that are engaged in processes (Bronfenbrenner 2005). From an ecological perspective, the person is one dynamic force that positively or negatively influences his or her development. The third tenet of Bronfenbrenner's theory is the context wherein the individual's development occurs (Bronfenbrenner 2005). It is also an influential force that affects the child's development. Bronfenbrenner and Morris (2006) identified contexts as consisting of
four nested environmental systems: microsystem, mesosystem, exosystem and macrosystem. (Figure 3.4)

This framework presented different levels or concentric systems of contextual influence in a child's development where each system has its own set of norms, rules and roles depending on the setting. At the most proximal level is the microsystem, which is the child's immediate context that most directly influences. These include the relationships a child has with people, for example parents, peers, teachers, the settings in which the child lives and grows and the material elements available. The next is the mesosystem, which encompasses the inter-relationships between all the elements in the microsystem, such as the parents' relationship with
one other, parent-professional relationships in a healthcare setting and work-home problems in arranging schedules. The third level is the exosystem, which involves the infrastructure of a city or region, including resources such as the availability of roads, utilities and police protections, as well as the capacity of the health and school systems to meet the specialised needs of a child with a disability. At the most distal level is the macrosystem, which brings us to culture, with all its beliefs, assumptions and practices concerning health, government, spirituality, values and the economy. The final tenet is the concept of time. It is also known as the chronosystem, which refers to “the person’s development of changes (and continuities) over time in the environment in which the person is living” (Bronfenbrenner 1989).

A critical characteristic of the ecological systems theory is based on the concept of “multiperson systems of interaction” (Bronfenbrenner 1989) and the developmental effects of the interrelations between these settings, both direct and indirect. The nature of the personal interaction at the microsystem level is influenced by the events and activities at the macrosystem level (Sontag 1996).

The main premise of Bronfenbrenner's theory is that “the properties of the person and of the environmental settings, and the processes taking place within and between them must be viewed as interdependent” (Bronfenbrenner 1989), with interactions reciprocal rather than unidirectional. Bronfenbrenner rejects laboratory settings for research, noting that they do not mirror real life and, instead, proposes multiple settings that have an increasingly distal influence on human behaviour. This makes it an especially useful model when exploring the perception of the term CP within the Saudi culture context. This model considers the child as the focus within the immediate context of his/her family, community and social services. Giving a great emphasis to the complexity of development and to the large number of environmental influences on children's development, it also views the family, along with their cultural background, as having a pivotal role in the development of their children. Bronfenbrenner's theory focuses on relationships and how children interact with other persons in different environments and how such interactions, or lack of them, influence development. However, the problems with relationships that disabled children encounter is that they are different to those of children without disabilities (Skär 2003).
Ecological theories, developed from Bronfenbrenner's theories, have been applied in different settings and researches (Smith and Taylor 1998; King et al. 1999; Jack 2000; Duncan et al. 2005). King et al. (1999) noted that the presence of social support was a significant predictor of parental well-being as characterised by less depression and stress in families of children with disabilities. Taken together, these results provide support for Bronfenbrenner (1989) ecological framework, which emphasises the influence of external factors on families' and children's well-being.

Jack (2000) applied ecological theory in parenting and informal support systems in situations of poverty. He described the development of children and young people and their subsequent life chances as the product of a complex set of interacting factors at individual, family and community levels, and applied an ecological framework to examine the mutual influences between the systems that are important during childhood. Application of an ecological framework in social work by Jack (2000) helps to explain a complex set of interactions between systems affecting children and young people and their life chances in adulthood.

Smith and Taylor's (1998) studied families in transition and the involvement of families in Family Court proceedings. The changing nature of families (divorce, separation, remarriage) is argued to be due to changing social and cultural values, in turn altered by other social and economic conditions. The authors show the significance of ecological theory and Bronfenbrenner's notion of mutual accommodation in terms of environmental context and children's experience within it (Smith and Taylor 1998).

Ecological theory has also been applied to family resilience. This study shows that families' experience of the practices within early childhood centres (microsystem) are supportive and provide a connection within a community of others outside the immediate family. The link with the mesosystem was identified as the quality of the relationships that early childhood centre staff have with families, advisory agencies and social agencies (Duncan et al. 2005).
A number of researchers, however, consider that the ecological model lacks attention to cognitive process and gives too little attention to biological foundations of development (Tudge et al. 2009; Watts et al. 2009). Moreover, they believe the theory does not address the step-by-step developmental changes that are the focus of theories such as Piaget’s and Erikson’s (Watts et al. 2009).

Tudge et al. (2009) provide a critique illustration in the use and misuse of Bronfenbrenner's bio-ecological theory. They reported that, for the most part, the research that cited Bronfenbrenner's theory was informed more by his earlier theoretical work, which focused more on context, than by his more recent theorising, which includes the central concept of proximal processes and his more nuanced attention to time.

In light of this evidence, I found Bronfenbrenner's ecological theory to be the most appropriate framework for the study. The perspective of the model seeks to identify the factors that influence the perception of CP and experience of the child (Kelly et al. 2000) with CP. As Kelly et al. (2000) state, the essence of the ecological perspective is to construct an understanding of the interrelationships of social processes of the group, organisations and communities in which we live and work.

3.4 Mothers of Children with Disability

Western studies showed that in 94–98% of cases, mothers are the primary caregivers and persons most knowledgeable about the health and needs of a child with a disability (Thyen et al. 1999; Brehaut et al. 2004; Montes and Halterman 2007). Further, the time and skill required to care adequately for such children are substantially greater than that required for caring for non-disabled children (Crowe and Florez 2006).

This section will focus on the literature review that provides insight into the context of disability and CP from the mother's perspective.
3.4.1 Mother’s Perception of Disability

Definitions of health and illness differ among cultures. How a disability is viewed varies by severity, impact on life, beliefs regarding aetiology and preferences for treatment (Salas-provance et al. 2002).

Parents' perceptions about the nature of their children's disabilities have been a focal point among different cultural groups (Mexican-American, Chinese American, South African, Turkish, Iranian, Arab and Bangladeshi) in several studies (Ryan and Smith 1989; Garcia et al. 2000; Masasa et al. 2005; Diken 2006a; Kermanshahi et al. 2008; Daudji et al. 2011). These studies showed that mothers of many cultures have been found to hold dual biomedical and traditional beliefs regarding the nature, causation and treatment of disability (Diken 2006b; Raman et al. 2010; Daudji et al. 2011). Conversely, many mothers may not perceive biomedical interventions as effective, or even necessary, or may not perceive their child as ‘disabled’ (Diken 2006b). Other mothers, especially those who believe in reincarnation, perceive their child’s condition as temporary (Danseco 1997). Accordingly, these mothers may be less likely to seek treatment for their children (Danseco 1997).

In a recent qualitative study, Daudji et al. (2011) explored the perceptions of disability among South Asian immigrant mothers of children with physical disabilities in a large multicultural urban centre in Ontario, Canada. They concluded that, in this population, mothers’ perceptions of their child’s disability were influenced both by traditional cultural notions of disability and by those imposed on them through institutional and societal norms within their new country. To help these mothers achieve a positive and realistic frame of reference for their child’s disability, Daudji et al. (2011) suggested that healthcare providers should play an important role in advocating for access to social supports and helping mothers set achievable goals for their child.

Similarly, Raman et al. (2010) examined the perceptions of ten Kuwaiti mothers with children with disabilities in order to understand the meaning of disability from their perspective and to explore the extent to which such perceptions influence rehabilitative services that their children receive. They found that Kuwaiti mothers may hold both the fatalistic view of disability and the belief that the course of
disability can be altered through a rehabilitative intervention. An appreciation of this phenomenon might move towards a rehabilitation delivery model that integrates and harmonises such beliefs.

These findings are consistent with previous research (Ryan and Smith 1989; García et al. 2000; Masasa et al. 2005; Diken 2006b) demonstrating that mothers of Mexican-American, Chinese-American, South African, Sri Lankan, Indian and Bangladeshi cultural origins hold dual biomedical and traditional beliefs regarding the nature and causation of disability. Moreover, the study found that the nature and cause of children with mental disability similar to those with physical disabilities (Diken 2006b). Diken (2006b) explored the disability perception of thirteen Turkish mothers who had at least one child with Mental Retardation (MR). Findings showed that the mothers held both traditional and bio-medical beliefs on the causation of the disability. Mothers identified traditional beliefs, especially the religious ones, as the most popular causal agents. Some mothers did not believe their children had a disability or misunderstood the nature of disability. Although most were aware of their children's developmental limitations, they, at the same time, perceived the condition of the disability as temporary.

Mothers' perceptions about the causes of disability have a tremendous impact on parents' behaviours in terms of seeking help or intervention for their children (Diken 2006b; Maloni et al. 2010). Both ‘biomedical' and 'traditional' health practices and beliefs may influence mothers' care-seeking behaviours (Maloni et al. 2010). Mothers' perceptions of traditional healing and biomedicine may influence the care they seek for their children. For example, a Turkish study by Diken (2006b) showed that mothers who perceived their child’s disability to be a result of a traditional cause were more likely to seek a traditional intervention, whereas mothers who perceived a biomedical cause of disability were more likely to pursue formal medical services (Diken 2006b).

Mothers' perceptions of disability may also be influenced by the attitudes of their family and community (Green 2003; Maloni et al. 2010). In a case study from the United States, researchers reported that mothers were more likely to feel embarrassed and guilty about their child’s disability if they themselves felt that people with disabilities were devalued and discriminated against in their community.
Additionally, the same research group found that mothers who experienced a great deal of stigma, related to their child’s disability, reported a higher burden of care for their child, were much less likely to interact with peers and were less likely to investigate age-matched interactions for their children (Green 2003).

Similarly, Maloni et al. (2010) described the perceptions of disability among eleven mothers of children with physical disabilities in Bangladesh and explored how these perceptions influenced the care sought for their children. The study found that participants were often conflicted between the ‘traditional’ and ‘biomedical’ explanations of disability due to multiple influences from family, elders and health professionals. Participants suggested that education and peer support networks provided in the rehabilitation setting played a critical role in addressing these conflicts (Maloni et al. 2010).

In summary, literatures indicated that although parents' perceptions on the nature of a disability may differ from each others', to some degree, based on their cultural values, they also hold similar views about the nature of a disability. Common perceptions include seeing their children as developing normally, identifying their children's condition as a temporary or passing condition, and perceiving a disability as God's punishment or, conversely, God's special gift.

Understanding mothers' perceptions of disability and treatment, and the myriad of factors that influence those perceptions, provides valuable knowledge to assist in planning and delivering family-centred rehabilitation services for children (Maloni et al. 2010). However, little is known about the perceptions of disability in the Middle East or Muslim countries and none of these literatures concerned Saudi mothers, where there is the potential for exposure to new values, influences and mediating factors.
3.4.2 Lived Experiences of Mothers of Children with CP

There is a large body of social science literature (Glasscock 2000; Sawin et al. 2003; Moore 2005; Jonathan et al. 2008; Huang et al. 2011; Appelbaum and Smolowitz 2012; Ahmed et al. 2013; Algood et al. 2013; Burkhard 2013) that has focused on the parents caring for children with chronic health conditions and disabilities. Within this literature, there has been a focus on the lived experience of mothers caring for a child with CP. However, these literatures are a small number of published and unpublished studies (Glasscock 2000; Moore 2005; Huang et al. 2011; Burkhard 2013).

Most researchers who examined the mother experience used a phenomenological approach. Glasscock (2000) examined fifteen mothers of a young child, aged 1 – 5 years, with spastic CP. In a master’s thesis, Moore (2005) examined the experiences of five mothers caring for young children, aged 4-11, with severe CP and intellectual disabilities. Huang et al. (2010) described the lived experience of fifteen Taiwanese mothers of children aged 8 months to 14 years after learning that their child had CP. In the follow up study for Huang et al. (2011), the challenging care-giving experiences were described. Lastly, Burkhard (2013) explored the lived experience of eleven mothers caring for an adolescent or young adult, aged 14 to 22 years, with severe CP.

All these studies illuminated the experiences that the mothers of children with CP are faced with, the unique challenges and parental stress. A crucial source of stress for many families who have children with CP is handling the continuous demands of their children. Mothers must deal with the normal challenges associated with daily life but also have to accommodate the demands associated with the child’s condition (Burkhard 2013). These continuous care-giving demands often lead to an alternation in the social functioning and recreational activities of mothers. Glasscock (2000) found the day-to-day care-giving was extraordinarily time-consuming and affected their daily living, as well as social activities. Mothers in the Burkhard study (2013) shared the challenges of caring for a child that required frequent medical appointments, hospitalisation, surgeries, therapy sessions and an intensive home exercise regime with the demands of caring for their other children.
Maintaining a balance between different roles creates tensions and family dysfunction in day-to-day activities. Balancing the role as caregiver, providing home therapy and undertaking the role as a parent creates strain on family relationships, including siblings, husbands and parents (Glasscock 2000; Moore 2005; Huang et al. 2011; Burkhard 2013). Moore suggested the presence of maternal concern for disrupted sibling relationships, namely sibling fear and jealousy, needs further reported exploration. Conversely, Burkhard (2013) reported that mothers, whilst having these concerns when their children were young, reported enhanced sibling relationships as their children moved into adolescence and young adulthood.

The care-giver burden was described in terms of mothers needing a great deal of time, energy and emotional strength to provide care (Glasscock 2000; Moore 2005; Huang et al. 2011; Burkhard 2013). Activities of daily living, such as ambulating, bathing, dressing, eating and drinking were all impaired to a significant degree for the children. Some of the differences in care were probably due to the differences in development that each child displayed (Moore 2005). High levels of burden were defined as children having a combination of characteristics that limited self-care skills, severe cognition issues, physical impairments or severe behavioural problems (Burkhard 2013). The burden of physical demands, placed on the mothers, varied according to the age of the child, with the older children being harder to care for because they were generally heavier and more difficult to care for physically (Glasscock 2000; Moore 2005). This physical burden, in turn, requires adaptive behaviour on the part of the mother in the physiological mode (Moore 2005). Burkhard (2013) reported that, as the children moved into adolescence and young adulthood, physiological changes were necessitated in both the mothers and their children to cope with the created additional challenges. As the physical care requirements of their child became the "norm", so the physical demands of caregiving increased, as well as the time taken to care for their child.

However, as the mothers adapted to caring for their child with CP, they were able to reveal positive parenting experiences and identified that the child was a source of that joy (Glasscock 2000; Moore 2005; Burkhard 2013). They also felt a deep sense of love and commitment for their child with CP (Moore 2005).
Learning of a child’s diagnosis of disability was perceived as a crisis for parents (Hatton et al. 2003). Mothers were reported to experience feeling out of control and powerless because of the loss of their ‘ideal’ child when their child was diagnosed with CP (Huang et al. 2010). They experienced a loss of expectations of ‘normal’ motherhood and fulfilling societal anticipation of giving birth to a healthy child, and failed to fulfil the anticipations of society of providing their children with a healthy body. This was an expectation that was necessary to maintain their husband’s family honour and prosperity, as well as saving face in their community. They experienced emotions of disbelief, rejection, sadness, crying and contemplated suicide because they felt no hope for the future. They also expressed feelings of uncertainty about their children’s future when health professionals did not empower them to completely understand the prognosis of CP (Huang et al. 2010).

Social support has been defined as information or social environmental conditions that enable an individual to feel loved and cared for, affirmed, or as belonging to a group of persons with common goals and beliefs (Schaefer et al. 1981). An individual’s perception of support is thought to be a characteristic related not only to the actual availability of support but also to the criteria that individuals use in interpreting behaviour as either supportive or non-supportive. Mothers of children with CP have voiced the conscious decision to surround themselves with supportive people (Glasscock 2000; Moore 2005; Burkhard 2013). Mothers were also noted to be highly engaged in the preservative love activities associated with health, safety and well-being but were also engaged in nurturing their child’s growth and facilitating social acceptability (Burkhard 2013). Conversely, having the perception of a lack of support from their community and some family members, the mothers’ conscious decision was to seek out and surround themselves with supportive extended family members, which was most often grandparents, and friends (Moore 2005).

In Glasscock (2000) and Moore (2005) studies, mothers identified socio-economic concerns associated with employment and financial status as a source of difficulty in caring for a child with CP. This, however, was not a dominant theme in other studies (Burkhard 2013). This may be because the mothers of the older children had already explored employment decisions by the time their child reached adolescence and
young adulthood. Thus, their families would have benefited from the financial security often associated with more time in the workforce.

Mothers of children with CP may also experience marginalisation in a variety of ways, both inside and outside the family (home, community, school, or society). Huang et al. (2011) reported that mothers of a child with CP were often blamed by family members. The investigators attributed this finding to the Chinese cultural belief, still held by many, that a parent, family member or ancestor may have done a “misdeed” that has caused the child’s disability.

To tackle the cultural emphasis on the negative aspects of a care-giver’s burden, Green (2007) sought to further examine the experiences of 81 mothers caring for preschool to high school-aged children with disabilities. This sample, with a child mean age of 5 years, included 31% of mothers caring for a child with CP. This study used a combination of quantitative and qualitative methods to examine how perceptions of stigma, objective burdens and subjective burdens affected the perceived benefits of caring for their children. The qualitative findings revealed that meeting the personal, medical, educational and social needs of a child with a disability, in the context of negative public attitudes and poorly coordinated service systems, can be physically exhausting and financially draining for mothers.

In summary, several studies have sought to explore, describe and interpret the mother’s experiences in the context of childhood CP. These investigations have focused primarily on western and Taiwanese mothers. To date, no published study has examined the maternal care-giving experience in Saudi mothers of a child with CP or a disability. This study will address these gaps and will particularly explore how mothers and children with CP experience disability. More specifically, this research will show how these experiences and perceptions can only be fully understood in relation to the specific complexity of Saudi culture. The next section focuses on stigma and disability.

3.5 Stigma, Disability and Culture

Stigma was seen as a relationship between an attitude and a stereotype that linked a person to undesirable characteristics, which manifested in social interaction
(Goffman 1963), but this notion of stigma does not take into account the impact of power differences. It can be argued that Goffman's (1963) view of stigma does not give much attention to inequalities between social groups, status and social class, as factors in stigmatisation.

In response to these criticisms, Link and Phelan (2001) proposed a sociological definition of stigma as the co-occurrence of its components — labelling, stereotyping, separation, status loss and discrimination', critically adding that for stigmatisation to occur 'power must be exercised'. Discrimination here does not simply refer to one individual's treatment of another, but to structural (or institutional) discrimination (i.e. a 'disabling environment') and to discrimination one or more steps removed from labelling and stereotyping, as when a loss of status occasioned by stigmatisation leads to a spiralling of disadvantage. Link and Phelan (2001:375) make power central: 'stigma is entirely dependent on social, economic, and political power – it takes power to stigmatise'.

Green et al. (2005) investigated the impact of these components of stigma in eight adults with disabilities and seven mothers of children with disabilities. Findings indicated that these social factors can negatively impact individuals with disabilities. However, this research study did not address the influence of culture, ethnicity and race associated with stigma.

More recently, anthropological contributions to the study of stigma have focused on stigma as embedded in moral experience and on the stigmatised as a person with a moral status (Coker 2005; McHatton and Correa 2005; Yang et al. 2007; Yang and Kleinman 2008). Yang et al. (2007) suggested that cultural norms influence what stigmatising attitudes will be assumed by a community. Additionally, researchers in Egypt found that people who held negative attitudes toward intellectual disabilities in Egypt also endorsed cultural norms in that community (Coker 2005).

Stigma not only affects the experiences of those in possession of the stigmatising characteristic, it also tends to spread to the others with whom the bearer of negative difference associates (Goffman 1963; Green and Rodgers 2001; McHatton and Correa 2005). According to Clements and Read (2008), stigmatising children with disability had extended to their families, disrupting family relations, especially if the disability was from birth (and therefore, often, more obvious). Other studies noted
that the mothers perceived a tremendous amount of stigma and discrimination as a result of either their culture or their children's disability, or in some instances a combination of the two (McHatton and Correa 2005). McHatton and Correa (2005) examined the perceptions of stigma and discrimination amongst 50 Mexican and Puerto-Rican single mothers. Findings showed that the mothers encountered discrimination from many different sources, such as from strangers and family members, and believed that educators and service providers were responsible for much of their discrimination. The mothers reported that a great deal of the discrimination that was directed toward them was because they were their children's primary caregivers.

Other areas of research looking at stigma have examined the negative outcome of the stigma. Green and Rodgers (2001) described that the way in which the effect of individual responses to stigmatisation and discrimination is important. Their study found that mothers of children with disabilities who feared discrimination were less likely or willing to interact with others. Their children were also less likely to interact with peers. This response has implications for both the mother and the child, possibly limiting opportunities and life chances. Green (2003) also extends the research to the experience of courtesy stigma in families of children with disabilities, using a mixed methods approach. Results of interactive interviews with seven mothers, along with author's experience as the mother of a child with CP, indicate that perceived stigma increases the subjective burden mothers perceive in their care-giving tasks. Subjective burden, in turn, decreases the frequency with which children interact with age peers. Stigma also exerts a direct effect on peer interactions when subjective burden and preference for interactions with wise individuals are controlled. Children of mothers who expect stigmatised reactions from others are less likely to interact with age peers on a regular basis, in the informal settings of homes and neighbourhoods (Green 2003).

In summary, Stigma can play an important role in the lives of individuals with disabilities and others who regularly associate with them. Evidence demonstrated that socio-cultural beliefs and norms can influence the content of stigmatising attitudes. Therefore, understanding the unique social and cultural processes that create stigma in the lived worlds of the stigmatised will be considered in this study.
3.6 Disability in Saudi Arabia

In Saudi Arabia, a person with disability is defined as:

― A person with a disability is 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.

"Persons with disabilities" shall refer to individuals who have one or more of the following disabilities: visual disability, hearing disability, cognitive disability, motor disability, learning disabilities, speech and language impairments, behavioural problems, pervasive developmental delay, multi-disabilities and other disabilities which require special care.” (Article 1 Disability code SA 2004)

3.6.1 The Rights of People with Disability in Saudi Arabia

The concern of the Saudi government for disability welfare and rehabilitation began in line with the social and economic development programmes for the Saudi State. Since this reform, the rights of disabled people have improved and resulted in the creation of comprehensive services and distinguished facilities for disabled persons throughout the country (Alsaif 2008).

Furthermore, the ministries of education, social affairs and health have been making concerted efforts to formulate policies and prepare organisational bylaws of special education and rehabilitation programmes in the Kingdom for disabled people. In 2000, the disability code was passed by the Saudi government to pledge that people with disabilities had access to free and appropriate medical, psychological, social, educational and rehabilitation services through public agencies (Al-Shehri and Abdel-fattah 2008). The following section discusses the disabled rights in Saudi Arabia including the right to work, the right to education and the right to care.
3.6.1.1 The Right to Work

The Kingdom's labour law stresses the right to work, for people with special needs. The law requires private sector employers who have 50 employees or more to employ 2% of the total workforce from people with special needs. This has provided people with special needs the opportunity to work and to participate and contribute to society. This right is well recognised in the public sector (i.e. government departments) and the Ministry of Civil Services pays special attention and gives particular consideration to job applications from people with special needs; the Ministry offers them suitable jobs once they graduate or complete their training.

3.6.1.2 The Right to Education

The Ministry of Education in Saudi Arabia is responsible for providing a free and appropriate education for all students, including those with disabilities. There are two major educational settings in Saudi Arabia; segregation, where students with disabilities receive their education in separate schools, and inclusion where students with disabilities receive their education in regular schools with their peers without disabilities. According to Alquraini (2010), 88% of students with mild disabilities, during the 2007/2008 academic year, received their education in an inclusive setting; however, 96% of students with multiple and severe disabilities received their education in private institutions.

Although, the disability code supports the equal rights of individuals with disabilities in obtaining free and appropriate education, these laws are not fully implemented in real world (Al-Jadid 2013). In fact, the lack of effective implementation has created a gap between the framework of these laws and the provision of services, resulting in a lack of special services for disabled people (Al-Jadid 2013). Moreover, the level of education for disabled persons continues to deteriorate, despite the Saudi government effort to encourage equality of educational opportunity for disabled students (Alsaif 2008). This might be due to the lack of qualified special educators in most schools, and the negative attitudes of people in schools towards children with disabilities were the main obstacles that hindered the effectiveness of inclusion programmes (Kashrami 2003).
3.6.1.3 The Right for Healthcare

The Ministry of Health is concerned with medical care, preventative measures to avoid disability and medical rehabilitation. The Ministry of Health has established numerous rehabilitative services for disabled people and other residents in the country. The majority of these programmes offer physical, occupational, speech and hearing therapies as well as prosthetic and orthotic services. Children with a disability who require assessment or therapy are usually taken to the local clinic or the nearest public hospital. Generally, most people attend MOH hospitals since healthcare is free and includes rehabilitation. All secondary and tertiary hospitals have rehabilitation therapists (i.e., physiotherapists, occupational therapists, speech therapists and dieticians). Not all district hospitals have therapists. If there is no therapist at the district hospital, the child is referred to the nearest hospital with a therapist.

3.6.2 Social Welfare in Saudi Arabia

The Ministry of Social Affairs is considered to be the main sector serving disabled persons. It provides rehabilitation programmes, social and vocational training programmes (Al-Maghlooth 1999). There are several disability centres supervised by the Ministry of Social Affairs, including three Vocational Rehabilitation Centres, three residential and Handicapped Social Rehabilitation Centres, two Paralysed Children's Care Institutions and sixteen Comprehensive Rehabilitation Centres. In 2009, the Ministry of Social Affairs introduced the day-care centre concept for disabled children. Currently, the Social Affairs Ministry supervises 16 day-care centres throughout the Kingdom (Ministry of Social Affairs 2014). However, these numbers of institutions and centres appear to fall short of the requirements for disabled persons, bearing in mind the institutions are largely available in urban, more than rural areas, with an uneven distribution of facilities unrelated to the distribution of persons with disabilities (Al-Jadid 2013).

Additionally, the Ministry of Social Affairs provides an aid programme for disabled children living with their families, which provides a maximum annual allowance of SR 10,000 (£1,600) for each disabled child. There is also an aid programme for persons with disabilities who are cared for by their own families, with a maximum
of SR 10,000 (£1,600) per annum for severe cases and SR 6,000 (£1,000) for those who do not benefit from vocational rehabilitation programmes (Ministry of Social Affairs 2014).

### 3.6.3 Trends in Disability Research in Saudi Arabia

Saudi research into disability is very limited, with the majority of research being in the form of dissertation studies conducted by Saudi students in the West. This section outlines the nature of disability research in Saudi Arabia and gives some examples. It also shows how disability has been represented in research conducted in Saudi Arabia.

Through an extensive literature search, I have found only two studies that have addressed mothers of children with disability. One recent study addressed the effects of children with disability on the mothers’ psychological status in Saudi Arabia (Al-eithan et al. 2010). This study included 75 mothers who had children with physical, mental or sensory disability and 35 mothers with healthy children. The findings of this study indicated that mothers of disabled children scored higher anxiety and depression compared to mothers with healthy children. The authors recommended further studies in different clinical settings to provide a more comprehensive picture of mood problems of mothers with disabled children in Saudi Arabia.

An older PhD thesis, by Khusaifan (2005), investigated the wellbeing of mothers of children with intellectual disabilities in Saudi Arabia. The research involved Saudi mothers of children with intellectual disabilities (ID) and focused on, stress, mental health status, ways of coping, social support provided to them and type of family structure preferred by them. Results from this study indicated that mothers of children with ID showed higher levels of stress, anxiety and depression than mothers of typically-developing children. Furthermore, behavioural disorders (BD) were significantly stronger than intelligence quotient (IQ) in predicting maternal outcomes (stress, mental health status, ways of coping, social support provided). Data also showed that religious coping had a moderating effect between BD and maternal stress, between BD and maternal anxiety and between IQ and maternal...
anxiety. Additionally, emotion-focused coping showed a significant moderating effect on BD and maternal anxiety. In terms of social support, the helpfulness of social support showed a significant moderating effect between IQ and maternal stress, whereas network size had a significant moderating effect between IQ and maternal stress.

Attitudes towards disabled children have also been addressed by Saudi scholars. A PhD thesis, by Zamzami (2005) explored the Pre-Service Physical Education (PPE) teachers' attitudes toward students with disabilities in regular educational settings in Saudi Arabia. He surveyed 403 male, physical education students, using Physical Educators' Attitude towards teaching individuals with disabilities. Findings from this study showed that PPE teachers had more favourable attitudes towards students with emotional/behavioural disorders than students with learning disabilities and mental impairments. Teachers' attitudes were more favourable towards teaching students with learning disabilities than students with mental impairments in regular education classes. Interestingly, the level of PPE teachers' education did not influence their attitude. PPE teachers who were educated in a junior college held more positive attitudes toward teaching students with disabilities than teachers who had a higher level education. The study also showed no significant differences in attitudes with personal interaction with individuals with disabilities and type of disability. However, Zamzami’s study was limited to males only, because the data was collected from the sole physical education college in Saudi Arabia for men.

Earlier studies conducted by Abdulwahab and Al-gain (2003) aimed to explore healthcare professionals‘ attitude towards people with disabilities. One hundred and thirty respondents were included from 4 hospitals, including King Faisal Specialist Hospital and Research Centre, King Kalid University Hospital, King Fahad National Guard Hospital and Security Forces Hospital in Riyadh city. The study showed that Saudi Arabian healthcare professionals displayed positive attitudes towards people with disabilities as do other professionals and caregivers worldwide. However, in this study the authors argued that these positive attitudes could be due to the influence of contact of the participants with disabled people. This contact appears to lessen the fear of the unknown and erase negative stereotypes. Moreover, they also stated that the positive attitudes toward people with disability may also be due to the
knowledge and education regarding disability issues. Furthermore, they also pointed out the positive attitudes of health professionals in this study. They discussed how they could be used to encourage non-disabled people, who have no contact or experience with disability, to treat a person with disability in a genuine, warm and accepting manner, and welcoming interaction. The limitation of this study includes a small sample size, based on four hospitals in one city. There were also only three healthcare disciplines involved in this study, with the majority of participants being physical therapists.

In 2000, Al-Hazmi conducted a national research study exploring disability in children in Saudi Arabia. This was one of the most extensively-funded research projects in Saudi Arabia and was sponsored by numerous funding agencies, involving many researchers. The aim of this research was to establish a database concerning the number of children with disabilities in different age groups and geographical areas of the country, to provide the government with information about the condition of children with disabilities in Saudi Arabia and establish new services and programmes for children with disabilities in the future. The results of the study indicated that the poor health conditions and the ages of mothers were the two reasons behind the birth of children with various mental and physical disabilities. One of the recommendations from the study was the importance of increasing pregnant women's awareness about their health conditions. Another recommendation was the importance of establishing libraries for children with disabilities. Books and other educational materials within these libraries should be available in audio and visual formats to allow for easy access. Moreover, they recommended that disability organisations offer training courses and workshops in different rehabilitation areas for special educators and caregivers to increase their educational levels and update their information about new issues in the disability field. As a final recommendation, Al-Hazmi (2000) argued that scholars and academics in Saudi Arabia should consider conducting more research in topics related to disability, including research about the prevalence and characteristics of disabilities in Saudi Arabia and research about disability organisations that exist in different parts of the country. Al-Hazmi's research is important because it established a database about disability in Saudi Arabia. His study detailed the types of physical impairments experienced and the limitations of people with disabilities.
The classifications of physical conditions also detailed people as patients. Therefore, this study focused on the physical aspects of people with disabilities. In other words, it focused on what people with disabilities were missing rather than what they had.

Finally, the PhD thesis by AlHammadi (2000) explored the needs of adults with disabilities in the Kingdom, from their perspective, using a mixed methodology. A sample of 200 individuals was examined, 82% of whom were males between the ages of 18 and 33. Participants in this study were predominantly within the physical disabilities category, with only 2% of participants with cognitive impairments. Information on the participants' perceptions on their healthcare, education, social integration, income, transportation, living arrangements and employment was collected. The findings from this study indicated that the majority of participants were dissatisfied with the affordable healthcare system provided to them. However, 75% felt they had good health and quality of life. The results also showed that participants felt that appropriate financial assistance would be needed for them to pursue higher education degrees. Participants indicated that the higher stipend should be made available to all individuals with a disability who pursue post-secondary degrees. Additionally, the participants reported that there is not enough social awareness of their needs and that it is important for them to feel safe in their homes and neighbourhoods. Furthermore, the findings indicate that only 50% of the sample drove a car, and 25% of the sample used a family car. However, the majority of the participants viewed transportation as a major obstacle, particularly due to the lack of accessibility in public transportation. It is important to note that despite the government mandate to make all public buildings accessible, this policy is rarely enforced by the state. 36% of the participants were unemployed and looking for work. Out of the 200 participants, only 61 received employment help from government agencies. Overall, the participants listed the following obstacles that hampered their employment opportunities: not being given a fair chance, transportation, lack of aid from employment agencies, low level of education and no government mandate that limits disability-based discrimination in employment. This study provided an important knowledge base about disability in Saudi Arabia. However, it focused on adults with disability.
Overall, disability research in Saudi Arabia has predominantly focused mainly on establishing disability prevalence rates as well as investigating the attitudes of various stakeholders regarding individuals with disabilities and their education. There are many difficulties associated with conducting research on disability related issues in KSA. Some cultural issues were that people feel ashamed of having disabled relative and tend to avoid participation in research (Al-Gain and Al-Abdulwahab 2002). Their opinions were based on a simple notion of disability that includes helplessness, continuing dependence, being home-bound, low quality of life and deficiency of productivity (Al-Gain and Al-Abdulwahab 2002).

3.7 Summary

This chapter explores the different perspectives that lie beneath the models of western disability studies and examines the contemporary disability movement's influence in redefining disability. Disability is analysed from the perspective of both disability theorists and disabled people and a critical evaluation is made concerning western definitions of disability and impairment. Bronfenbrenner's ecological theory has been reviewed, including the features Process, Person, Contexts and Time. The current literature on the mothers' perception and experience, stigma and trend in disability research in Saudi Arabia is also reviewed.

It can be seen from the above literature review that cultural background has been found to be a factor in the understanding and interpretation of the mothers' perception and experiences. The literature exploring Saudi research in children with disability is very limited. The majority of studies have focused on teachers' attitudes toward persons with disabilities, and explored the health and medical aspects of disability. There is a lack of research describing mothers' children with CP and the mothers' perception and experiences in Saudi Arabia. This study seeks to locate itself within a philosophy which takes into account the models of disability and Bronfenbrenner's ecological theory. The next chapter outlines the literature relevant to children and disability.
Chapter 4: Children and Childhood

4.1 Introduction

Since this research is rooted within an approach that aims to listen to children’s views, the voice of the child is fundamentally important within the project. This chapter reviews the relevant literature regarding research with children, and the importance of doing research with children. It presents the available research evidence on children’s experiences, the perceptive of disability, and child welfare in Saudi Arabia. Finally.

4.2 Childhood Sociology

Prior to the 1980s, researchers investigating issues of childhood rarely considered children as having the potential to be competent or valid research participants. Instead, they were conceptualized as being developmentally immature and incomplete (Freeman and Mathison 2009) and as “adults in training” (Shucksmith and Hendry 1998). Moreover, the voices of disabled children themselves were frequently excluded, and the researcher learned about the lives of children by proxy, through parents, teachers and other adults (Christensen and James 2000; Lloyd-Smith and Tarr 2000). Particular exclusion has been experienced by the children and young people who do not use speech as their first mode of communication and/or are perceived as having significant cognitive impairments (Morris 1998; Morris 2003).

Sociologists of childhood have emphasized the need to recognize children as social actors (Pole et al. 1999; Harden et al. 2000; Roberts 2000; Connors and Stalker 2003) who are capable of commenting on their own experiences and who have a basic right to be heard (Ireland Lorraine 1996; Shaw 1996; Lloyd-Smith and Tarr 2000). These assertions have caused radical shifts in thinking about childhood and children (James et al. 1998; Christensen and James 2000;). Children are now recognized as active agents in research (Connors and Stalker 2003; Rabiee et al.
2005). As more researchers have changed their ways of thinking about children, there has not only been a rise in the number of studies which feature them as active participants, but also an increase in the use of methodologies thought to help take advantage of their skills and insights (France et al. 2000; Lewis and Lindsay 2000).

The new sociology of childhood, according to Mayall (2002), works towards including children as _participant agents in social research_ and as a _social group fundamentally implicated in social relational research_ (p. 1). Mayall (2002) explains that _trying to think from children’s lives_ (p. 4) is the fundamental aim of the new sociology of childhood, which aims to _help improve the social and political status of childhood_ (p. 4). In this study, the new sociology of childhood provides a way of understanding children’s views and perspectives.

### 4.3 Power Relationship

Children and adolescents constitute a highly vulnerable group of potential research participants. This is largely due to their lack of developmental and cognitive maturity, their lack of authority and control in medical settings, and their dependence on parents and health care providers to make informed decisions about their research participation (James and Prout 1997). It is generally assumed that children lack the cognitive maturity and moral development to be able to understand, and make an informed decision to participate in, research (France 2004). When disability is added to the equation, the level of vulnerability increases and issue of power relations becomes even more acute (Bricher 1999).

Power imbalances have been widely recognized as being the biggest ethical obstacle and challenge to researchers including children in research (Alderson 1995; Morrow and Richards 1996; Thomas and O’Kane 1998; Mayall 2000). Power has tended to be viewed as something that adults have more of than children. According to Kirk (2007), the adult—enteredness” of most societies and the unequal power relations that exist between children and adults are reproduced during research. So children may experience pressure, which is not conscious but a result of the power relationships that are reproduced, and will not feel free to refuse participation, leave
in the middle of the research, or express their own opinions and share freely their experiences (McCrum and Bernal 1994). Additionally, in most studies where a child is under 16 years of age, parents or other adults act as gatekeepers giving consent to their child's participation and as protectors who may deny children the opportunity for participation or, on the other hand, force them into participation (Harden et al. 2000), resulting in feelings of conflict, guilt, reduced self-esteem, and fear of failure or embarrassment (Kirk 2007). These power relations are inherent and somehow predefine behaviours and expectations. As in all societies, power structures are manifested in all social relationships, such as gender, age, class, and ethnicity. According to Christensen (2004), viewing power as inherent to research emphasizes that research is a practice that is part of social life rather than an external contemplation of it. This requires the researcher to pay attention to broader issues of social and cultural life that are, or can be, sensitive to the issue of power.

Gallaghera (2008) suggested that a revised model of power needs to account for the fact that on one hand, adults appear to be more powerful than children, and on the other hand recognize that this generalised domination does not preclude multiple points of resistance and confrontation at which children are able to exercise power over adults. He argued that power is best viewed as a form of action, carried out through multivalent strategies and tactics, rather than a commodity or a capacity. Moreover, children should be viewed, not as vulnerable passive victims, but as social actors who can play a part in the decision to participate in research. Such a view would result in more careful attention to communicating effectively with children about research, and ensuring that they may have a more central role in decision-making about participation (Powell and Smith 2009).

### 4.4 Seeking the Voice of the Children

The importance of listening to children is well supported both within legislation (Children ACT 2004) and through the literature (Lewis and Lindsay 2000; Clark and Statham 2005; Aston and Lambert 2010). This involves dimensions of listening to children's views and fostering participation and empowerment. Mcleod (2007) suggested that listening to children is not just a matter of common sense or legal
obligation, but a fundamental human right. The United Nations Convention on the Rights of the Child (Unicef 2000) highlighted the fundamental right of participation and empowerment for all children. Articles 12 and 13 directed attention to the ‘voice of the child’ and a need for an appropriate means of communication. Acknowledgment was given that children are capable of forming views, have a right to receive and provide information, to express an opinion and to have that opinion taken into account in all matters affecting them. This was legally reinforced by the Children Act 1989. The Children Act 1989 and Quality Protects (Department of Health 1999) both stress the importance of ascertaining the wishes and feelings of children, including disabled children, and involving them in decisions about their care and welfare. The Department of Health (2002) has also issued guidance underlining its commitment to involving children in all aspects of its work (Rabiee et al. 2005). More recently, the National Service Framework for Children Standard for Hospital Services (Department of Health 2003) stated that provision should be made to involve children with communication difficulties in decision-making. As a result of these legislative statements, many children in general are more involved in policy-making, but children with disabilities continue to be excluded (Morris 2003; Cavet and Sloper 2004; Rabiee et al. 2005). In particular exclusion has been experienced by children and young people who do not use speech as their first mode of communication and/or those who are perceived as having significant cognitive impairments (Morris 1998; Morris 2003).

Researchers seeking the views of disabled children have used a variety of methods depending on the age and functional abilities of the children. These include Talking Mats, participant observation in school settings, drawings, spidergrams, sentence completion tasks, (postal) questionnaires, focus groups and semi-structured interviews or ‘structured conversations’ with the children. Often these methods are used in the presence of parents, carers or teachers, who may also be interviewed (Murphy 1998; Lightfoot et al. 1999; Watson et al. 2000; Davis and Watson 2001; Connors and Stalker 2003; Skär 2003; Macarthur et al. 2007; Woolfson et al. 2007). Talking Mats, developed by the Augmentative and Alternative Communication (AAC) Research Unit at the University of Stirling, is a visual framework that uses picture symbols to help people with a communication difficulty. Talking Mats have been used in research to find the views of children who lack speech, regarding their
social care and support service priorities (Rabiee et al. 2005; Hooton and Westaway 2008). In clinical practice they have been to enable a young man to report details of sexual abuse (Venditozzi 2007).

There are a range of studies demonstrating that children with disabilities and communication difficulties are often overlooked in planning and decision-making processes that directly affect them. Primarily, their opinions continue to be expressed by those adults who are close to them, such as their parents and school support staff, although their perspectives and experiences can differ from those of the children themselves (Garth and Aroni 2003; Sloper et al. 2009) and are therefore somewhat second hand (Mitchell and Sloper 2001). Beresford (2002) argued that if disabled children are not taking part in decisions about their own life, then it is a long leap for them to have the skills, confidence, self-esteem and empowerment to be able to participate in decisions about services.

On the other hand, there is a growing body of literature that emphasises the capabilities of children in being able to make valuable contributions to decisions about their care and service development (Alderson et al. 2006; Franklin and Sloper 2006). Franklin and Sloper (2006), from their survey of social care services, reported that 31 out of 70 initiatives indicted changes to services as a result of disabled children and young people’s participation. Most changes were reported to be altering activities or changes to décor, however for a small number, improvements were made in information provision for disabled children and young people. Lightfoot and Sloper (2003) investigated the extent and nature of involvement of physically disabled and/or chronically ill children and young people in health service development. They surveyed all local health authorities and NHS health Trusts and identified 27 initiatives across England. These included seeking their views to inform developments in: hospital inpatient, outpatient and community services, transition to adult services, and information needs for disabled young people. Seventeen of the initiatives reported that children’s involvement had resulted in changes; 11 reported that they went beyond consultation to involve children in the actual decision-making process about services.
Inclusion and participation of children and young people with impairments in the research process is seen by researchers as having some benefits for the young participants (Watson et al. 2000; Morris 2003; Badham 2004; Cavet and Sloper 2004). Morris (2003) reports a growth in the confidence and skills of children with impairments who participated in public decision-making. She examined four research projects that were undertaken to find out the views of disabled children and young people. All four research projects reviewed by Morris (2003), involved the conduct of interviews with young disabled people and consultation with a reference group of young disabled people.

In summary, the importance of listening to children is well supported in the literature. However, most of the literature adopted different tools and methods to be used for consulting children with disabilities. Although some researchers have been more willing to consider the views of young people with disabilities and accept the right of these young people to participate in decisions and debates that affect their lives, there is still evidence that they are not being listened to (Morris 1998; Watson et al. 2000). Hence, Watson et al. (2000) have argued for more research to be conducted from the perspectives of young people with disabilities that will challenge the universal concept of a homogeneous “disabled child” and lead to a more nuanced understanding of their lives.

4.5 Children’s Experiences and Perspective of Disability

The issue of how children perceive the disability is fertile ground for numerous challenging research questions. However, a small number of studies have sought the views and experiences of disabled children engaging simultaneously with new approaches to the study of disability and new approaches to the study of childhood (Garth and Aroni 2003; Skär 2003; Connors and Stalker 2007).

Evidence emerging from these recent studies promoting this approach suggests that for physically disabled young people, being disabled is part of life and they simply see themselves as “normal teenagers” (Watson et al. 2000; Skär 2003; Connors and Stalker 2007), often rating other disabled young people as being more disabled than themselves (Lewis et al. 2005). These perceptions can be affected by the
environment they are in, becoming more negative if an environment places barriers which highlight their impairment (Skär 2003; Connors and Stalker 2007).

This section, will review four recent studies that explored the experiences and perceptions of disabled children based on western culture and consumerism.

In a rare and recent study of the impact of disability on the day-to-day lives of children and their siblings, Connors and Stalker (2007) explored the lived experiences of 26 disabled children aged 7–15. The aims of the study were to explore disabled children’s understanding of disability, the ways they negotiated the experience of disability in their daily lives, and their perception of their relationships with professionals and their knowledge and views of services provided.

The findings suggested that children experienced disability in four ways in terms of impairment, difference, other people's behaviour towards them, and material barriers. Most young people presented themselves as similar to non-disabled children. Connors and Stalker (2007) offer several possible explanations for this focus on ‘sameness’ by the disabled children: they are minimizing or denying their differences; the children are active agents resisting disabling barriers and attitudes and showing their perception that their impairments and disability are not the defining features of their identity; or the children did not have adequate language or concepts to discuss their differences. They also argued that Youth culture and consumerism exert heavy pressure on young people to follow the crowd, keep up with others, and not to stand out. It is possible that all these explanations and others (for example ‘difference’ is not viewed positively and is therefore resisted) may have a role to play, to different degrees for different children, due to the acknowledged heterogeneity of the disabled children and variance in their understanding and viewpoints dependent on such factors as their age, ability and experience.

Moreover, Connors and Stalker (2007) noticed that the children’s accounts of their lives differ significantly from those of the parents’, which tend to be considerably more negative. The children were generally positive about their lives, whilst identifying problems of immediate relevance such as boredom experienced at home.
and a lack of socializing opportunities with their peer group, whilst parents reported instances when the child had been discriminated against or treated badly. This emphasizes the importance of seeking the views of children directly from them, rather than relying on reports from the caregiver or parent, who have different perspectives.

The concept of ‘sameness’ was also reported by Skär (2003), who found that the adolescents’ understanding of themselves did not always correspond well with how others saw them. Skär (2003) explored how adolescents perceived themselves, in order to enhance the knowledge of what it is like to grow up with a disability. She interviewed 12 adolescents with restricted mobility, aged from 15 to 19 years. The results indicated that disabled adolescents saw themselves as regular members of the adolescent peer group, just like all teenagers.

Similar findings about disability and their complex understanding of disability were shared in a study by Watson et al. (2000), who noted that young people with milder impairments often wanted to exclude themselves from the ‘disabled’ category, as they did not identify with it. These attitudes or pressures would tend to discourage children from talking about difference.

Watson et al. (2000) was one of the major studies in the field of child disability. It was carried out between 1997 and 1999, where 7 researchers in 14 schools, including both mainstream and special schools in England and Scotland, studied some 300 children aged between 2 and 16 years. The findings of the study highlighted four key themes: A striking feature of the study was the high degree of surveillance by adults which was experienced by the disabled children, which affected their privacy and influenced their relationships with non-disabled peers and which was actively resisted by some of the children. However, the study also found disabled children resisting such surveillance at times, and witnessed their attempts to reassert their own values and autonomy. The second was that the categorisation of children as disabled also formed part of the adult world, which bounded children’s experiences, while the children themselves were more ambivalent about the use of the category of ‘disabled’ both in relation to themselves and to others, suggesting their perspectives were based on experience and context. The third theme was limited relationships with peers due to physical, attitudinal and communication
barriers. The last theme was the fluidity of the young people's identification with disability (i.e. they did not always see themselves as disabled in every situation), compared to the tendency of adults to give primary emphasis to disability when dealing with them.

Watson et al. (2000) have argued for more research to be conducted from the perspectives of young people with disabilities that will challenge the universal concept of a homogeneous “disabled child” and lead to a more nuanced understanding of their lives. The researchers concluded that young people are the experts on their lives, and that the adults working with them should reflect their own practice and be prepared to consult with and learn from them.

Disabled children's experience of making friendships has been explored by Wickenden (2011). He focused on 9 children with CP, aged between 10-15 years in England who have little or no speech and who use Alternative and Augmentative Communication. The main methods were participant observation and individual extended narrative conversations, supported by various visual techniques such as mind-mapping and photography. The findings were similar to Watson et al. (2000), Skär (2003) and Connors and Stalker (2007): the disabled teenagers who have little or no speech see themselves as ‘normal teenagers’ and as people who have many of the same interests as their nondisabled peers. Like their contemporaries they are keen to be seen as sociable, funny and friendly and as they move into their mid-teens, they increasingly want to do things as independently as possible with friends and without adults present. They have a clear idea of what friendships should be like and have plenty of advice about how other people could help them to achieve these.

Wickenden (2011) argued that it is the children’s social-relational selves which are ‘normal’, even if their bodies are different. They use the term ‘normal’ quite insistently, without any suggestion at this stage that the concept in itself might be tyrannical. It is also interesting that they have strong feelings about being wrongly judged as having learning difficulties, something they see as negative. This hints at a hierarchy of impairments and disabilities attitudes, which have been observed between disabled people with different impairments (Deal 2003).
Regardless of how disabled young people view their impairment, it has been shown that they have strong views in relation to health, education, and leisure (Stone 2001), and wish to be consulted about them (Detheridge 2000; Hill et al. 2004; Kelly 2005). Disabled children and young people also want to be included and informed by the services they use. Garth and Aroni (2003), in a qualitative pilot study, interviewed four children who have cerebral palsy, and six mothers of children with cerebral palsy, about their perceptions and experiences of communication in medical consultations. The results support the findings of Connors and Stalker (2007) study and showed that while the children and mothers had similar views about the importance of communication, there were obvious differences in what was perceived to be important. Children felt strongly about being included in the medical consultation and perceived that inclusion was important, even if they did not understand what was being said. This further reiterates the importance of gaining the child's perspective when conducting research into their experiences, not just the parent's.

In summary, there has been increasing recognition of the fact that children's views differ from those of adults and there is now a body of research, which has obtained the views of disabled children, acknowledging that children with disabilities are experts on their life. This present study has been conducted from the perspective that disabled children in Saudi have a right to full engagement and participation in research, and a belief that there is a need for research into their views and experience.

4.6 Child welfare in Saudi Arabia

Children are considered the future of the society, therefore the Saudi government strives to ensure children live with dignity and pride right from birth. Also, it takes into account their right to live as human beings and their right to obtain necessary services such as education, medical treatment, housing and other requirements.

In 1996, Saudi Arabia signed and ratified the United Nations Convention on the Rights of the Child (CRC), but with reservations on Articles that are contrary to the provisions of Islam and considers it to be a valid source of domestic law (The
One of the government efforts in welfare has been to establish several committees to help children. In 1979 a specialist commission was established by the government under the name of the National Saudi Commission for Childhood. The main object of this commission was to set policies for children in Saudi Arabia, to plan programmes for their needs, and to coordinate the government with public organizations concerned with childhood in Saudi Arabia (Ministry of Education 2011). However, these committees have directed their efforts to issues concerning children outside the home, and have taken little consideration of the risk that children suffer in the home. Recently in 2005 a new programme was launched entitled the National Family Safety Programme (the National Family Safety Programme 2014). The goal of this unique program is to support and raise awareness and build partnerships with professional specialists and governmental and private institutions and international organizations to provide safe family environment in the Kingdom of Saudi Arabia (the National Family Safety Programme 2014).

Incidents of child abuse are fairly common in Saudi Arabia, about 70 cases are reported annually (Al Eissa and Almuneef 2010). To fight against this scourge, the National Family Safety Program have recently launched a campaign against child abuse that will last for three months. The “White Campaign” aims to pass a law against child abusers and raise awareness on this phenomenon. The campaign also seeks to educate children and their parents about ways of protecting children and to encourage standing up to such crimes. It also sheds light on psychological remedies to help victims of child abuse (Arab News 2013).
In addition to this, Saudi Arabia provides free education and free health care for all their citizens, which is particularly positive for children, given their health care needs during the first few years of their lives. However, these rights and regulations are not always practiced on the ground. Although children's rights have changed in law and policy, social attitudes toward girls are almost static. For example, families often believe it is their right to decide whether their daughters should go to school or not. Other issues are also regarded as family matters, such as the age of marriage or whether a girl should go out to work, as well as their right to choose their education (Belarbi 1996).

4.8 Summary

The reviewed research suggests that the perspectives of children are absent, and that most research has tended to treat children as the passive recipients of social capital, which was measured by quantifying their parents' social networks. Furthermore, in recent years there has been a growing body of literature that identifies the importance of including children in research. Several researchers have referred to the UN Convention on Rights of the Child, acknowledging that children hold the right to express their opinions about issues affecting them and the right to have these views heard.

The following chapter reviews cerebral palsy (CP) as a medical concept and its management.
Chapter 5: Overview of Cerebral Palsy

5.1 Introduction

This chapter will provide an overview of Cerebral Palsy. Discussion will include the definition of CP and the relevant epidemiology and classification. It will also describe risk factors and present the incidence and prevalence of CP in addition to the clinical presentation and problems associated with CP. The conclusion will include a critical review of current management approaches for children with CP, including medical and therapeutic interventions.

5.2 Definition of Cerebral Palsy

Cerebral palsy is one of the most severe childhood disabilities, and it can make heavy demands on health, educational, and social services, as well as on families and children themselves (SCPE 2000).

CP was first reported by William Little in 1861 and was initially called Little's disease (Shapiro 2004). It was described as a disorder that appeared in the first year of life, affected developmental skill progression, and did not improve over time. Originally Little linked the disorder to a lack of oxygen during birth (Jones et al. 2007). It was later suggested that it may occur in utero, affecting the brain's development as a result of factors influencing the developing foetus (Accardo 1982). More recently Mac-Keith and Polani (1959) defined CP as 

\[ \text{a persisting but not unchanging disorder of movement and posture, appearing in the early years of life and due to a non-progressive disorder of the brain, the result of interference during its development.} \]

This was further modified in 1964, by Bax who defined CP as 

\[ \text{a disorder of movement and posture due to a defect or lesion of the immature brain.} \]

(Morris 2007).

The heterogeneity of disorders covered by the term CP, as well as advances in the understanding of development in infants with early brain damage, led Mutch et al.
(1992) to modify the definition of CP to an umbrella term covering a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of development” (Mutch et al. 1992). More recently, the United Cerebral Palsy (UCP) Executive Committee for the Definition of CP proposed an updated definition in light of emerging understanding of developmental neurobiology and changing conceptualizations about impairments, functional status, and communication. The updated definition of the disorder, which is well accepted and frequently cited in the literature, defines CP as:

“Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitations, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, behaviour, by epilepsy and by secondary musculoskeletal problems” (Rosenbaum et al. 2007).

CP, except in the mildest forms, can be recognised in the first 12 to 18 months of life (Palmer 2004a; Bax et al. 2005). The condition is diagnosed when a child fails to reach their motor milestones and when they show unusual motor patterns and development, such as asymmetry, or unusual muscle stiffness or floppiness.

**5.3 Incidence and Prevalence of Cerebral Palsy**

CP is the leading cause of physical disability in children with an incidence of 2 to 2.5 per 1,000 live births (Reddihough and Collins 2003). There is an increased risk to boys, with a male to female ratio of around 1.4:1 (Odding et al. 2006). This may be due to the greater biological vulnerability of the male brain to injury, particularly preterm (Johnston and Hagberg 2007). There is also a clear social class gradient in the prevalence of CP as a whole, and in the subgroups hemiplegia and diplegia. Among normal birth weight cases there is a strong association with social class (Odding et al., 2006). In the UK, the prevalence of CP is higher in more deprived communities.
areas 3.33 per 1000 births in compared to 2.08 per 1000 in the least deprived areas (Dolk et al. 2001).

The rate of CP is much higher in preterm than term infants and increases with lower birth weight and gestational age (Lorenz et al. 1998; Wood et al. 2000; Johnson 2002). Fifty percent of children with cerebral palsy are born before 36 weeks gestation. However, one in every 1,000 babies born at full term will have cerebral palsy (Bax and Brown 2004).

Bax and Brown (2004) also suggest that there may be a genetic tendency for the brain to be vulnerable to hypoxic damage to the nerve cells and that more than one causal factor is often involved (Bax and Brown 2004).

In Saudi Arabia, there are several studies investigating the incidence of CP (Al-Asmari et al. 2006; Al-Rajeh et al. 1995; Al Salloum et al. 2011). However, agreement on incidence and prevalence levels in Saudi Arabia has yet to be established. One of the more recent study conducted by Al Salloum et al. (2011), aimed to establish the prevalence of neurologic disorders in the Kingdom of Saudi Arabia. CP was identified as the most common neurologic disorder among Saudi children with a prevalence rate of 2.34 per 1000. According to this study, the prevalence of CP in Saudi Arabia is within the range of the prevalence rates of CP in the UK. In the UK the prevalence pooled data from five active cerebral palsy registers in the UK suggest a mean annual prevalence rate of 2.0 per 1,000 live births for birth years 1986-1996 (Surman et al., 2006).

There are very few studies reporting data on the incidence rates of CP in Saudi Arabia (EL Rifai et al. 1984; Al-Asmari et al. 2006). Al-Asmari et al. (2006), suggested that the incidence of CP was 4.1 per 1,000 live births. However, this study, was only conducted at Riyadh Military Hospital and therefore only provides partial information. The reported incidence was relatively high compared to western countries reporting.

However, despite the limited statistical data the literature does suggest that CP is one of the most common paediatric neurologic disorders.
5.4 Causes of Cerebral Palsy

The causes of cerebral palsy are the subject of much debate and controversy, with approximately 50% of CP cases lacking any identifiable underlying aetiology (Nelson 2003). The etiology of CP is multifactorial, and it can result from brain injury occurring during the prenatal, perinatal, or postnatal periods (Nelson 1989; Gibson et al. 2003; Jones et al. 2007). In 75% - 80% of cases, CP is acquired prenatally (Krigger 2006), and more specifically identified within premature births between 20 to 30 gestational weeks (MacLennan 1999; Mayston 2001). In about 10% to 20% of patients, CP is acquired postnatally (MacLennan 1999), resulting from brain damage from bacterial meningitis, viral encephalitis, hyperbilirubinemia, motor vehicle collisions, falls, or child abuse (Krigger 2006).

A recent systematic review by McIntyre et al. (2012) identifies the risk factors for CP in children born at term. The analysis found ten significant risk factors for term-born infants, including placental abnormalities, major and minor birth defects, low birth weight, meconium aspiration, instrumental/emergency Caesarean delivery, birth asphyxia, neonatal seizures, respiratory distress syndrome, hypoglycaemia, and neonatal infections (McIntyre et al. 2012). Table 5.1 demonstrates the list of causes of CP in relation to each developmental period: prenatal, perinatal and postnatal.
### Table 5.1 The list of causes and risk factors associated with cerebral palsy

<table>
<thead>
<tr>
<th>Prenatal</th>
<th>Perinatal</th>
<th>Postnatal</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Hypoxia</td>
<td>• Asphyxia</td>
<td>• Asphyxia</td>
</tr>
<tr>
<td>• Genetic disorders</td>
<td>• Premature birth (&lt;32 weeks or &lt;2500 g)</td>
<td>• Seizures within 48 hours of birth</td>
</tr>
<tr>
<td>• Metabolic disorders</td>
<td>• Blood incompatibility</td>
<td>• Cerebral infarction</td>
</tr>
<tr>
<td>• Multiple gestation</td>
<td>• Infection</td>
<td>• Hyperbilirubinemia</td>
</tr>
<tr>
<td>• Intrauterine infections</td>
<td>• Abnormal fetal presentation</td>
<td>• Sepsis</td>
</tr>
<tr>
<td>• Thrombophilic disorders</td>
<td>• Placental abruption</td>
<td>• Respiratory distress syndrome/chronic lung</td>
</tr>
<tr>
<td>• Teratogenic exposure</td>
<td>• Instrument delivery</td>
<td>disease</td>
</tr>
<tr>
<td>• Chorioamnionitis</td>
<td></td>
<td>• Meningitis</td>
</tr>
<tr>
<td>• Maternal fever</td>
<td></td>
<td>• Postnatal steroids</td>
</tr>
<tr>
<td>• Exposure to toxins</td>
<td></td>
<td>• Intraventricular hemorrhage</td>
</tr>
<tr>
<td>• Malformation of brain structures</td>
<td></td>
<td>• Periventricular leukomalacia</td>
</tr>
<tr>
<td>• Intrauterine growth restriction</td>
<td></td>
<td>• Shaken baby syndrome</td>
</tr>
<tr>
<td>• Abdominal trauma</td>
<td></td>
<td>• Head injury</td>
</tr>
<tr>
<td>• Vascular insults</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The Data in the above table were compiled from a range of studies (Nelson 1989; Kuban and Leviton 1994; Han et al. 2002; Gibson et al. 2003; Jones et al. 2007; McIntyre et al. 2012)

The risk factors of CP in Saudi Arabia have also been explored by several researchers (Al-Asmari et al. 2006; Al-Rajeh et al. 1991; Al-Rajeh et al. 1995; Al-Sulaiman et al. 2003; EL Rifai et al. 1984a; EL Rifai et al. 1984c). Early work by Al-Rajeh et al. (1991) suggested that the major risk factors identified were a history of CP in a sibling and consanguinity of the parents. Later work has added to this body of knowledge and identified additional risk factors. EL Rifai et al. (1984a) who found that half of the children's brain damage (49.5%) was due to natal factors and that prenatal and postnatal factors accounted for 33.1% and 17.4% of risk respectively. More recent work by Al-Sulaiman et al. (2003) described the clinical profile, and identified risk factors, of CP from a cohort of Saudi children aged between one and 3 years of age. The main risk factors were identified as: twins (25%), low birth weight, and pre-term delivery (20%).
5.5 Cerebral Palsy Classification

CP has been classified in different ways, the traditional classification being related to the nature of the movement disorder and including: spastic, ataxic, athetotic and dystonic CP (Cans 2000; Sanger et al. 2003). Spastic CP is the most common type and accounts for 70%-80% of all cases, followed by dyskinetic at 10% to 15%, and ataxic is less than 5% of cases (Hagberg et al. 2001). The types of CP are outlined in further detail below:

- Spastic CP results from involvement of the motor cortex or white matter projections to and from cortical sensor motor areas of the brain (Sanger et al. 2003).
- The ataxic type of CP is categorized by damage to the cerebellum and problems with balance and coordinated movements are evident (Kandel and Schwartz 2013). Ataxic type CP is characterised by both abnormal posture and/or movement as well as loss of muscle control so that movements are performed with abnormal force, rhythm and accuracy (Gene l et al. 2014).
- Athetotic or dyskinetic CP is a disorder characterized by slow, unintentional or uncontrolled writhing movements caused by a lesion to the extrapyramidal system (Cans et al. 2007; Sanger et al. 2010). Dyskinetic CP however, can be dystonic or choreo-athetoic (Gene l et al. 2014).
- Mixed type is used for individuals who do not fit into the above classifications (Cans et al. 2007) and can be a combination of any of the aforementioned types, but the most common is a combination of spastic and athetoid (Cans et al. 2007).

CP can also be classified according to topographic distribution of abnormal muscle tone, posture or movement (Cans 2000; Koman et al. 2004; Bax et al. 2005). Commonly used topographic distribution includes: diplegia, hemiplegia and quadriplegia (Mayston 2001; Shevell et al. 2003; Jones et al. 2007).

- Quadriplegia is the most severe form. It involves all four limbs along with the trunk, and the upper extremities are involved more than the lower extremities.
- Diplegia, in which the lower limbs are more severely affected than the upper limbs, is the most common anatomical type.
• Hemiplegia is defined as involvement of ipsilateral upper and lower limbs, with the upper limb more severely affected than the lower limb, hand function being most affected.

• Monoplegia, which affects one upper limb, or triplegia, which affects three limbs, are two additional manifestations of CP. Monoplegia and triplegia are relatively uncommon.

Figure 5.1 Topographic classification of cerebral palsy

Although these designations focus on the limbs, involvement of the head and trunk muscles is typical. A more recent European classification designates spastic CP as bilateral or unilateral (Cans 2000). Lack of standardized definitions for topographic designations limits their reliability and validity (Gorter et al. 2004). This model of classifying CP is still widely used today (Hutton et al. 2000). However, this classification does not take into account the degree of involvement.

The severity of movement disability can be classified into levels I-V using the Gross Motor Function Classification System (GMFCS), a system with well-established reliability and validity (Palisano et al. 1997). The GMFCS is the most widely used
objective functional scale to sort individuals with CP into one of five levels of severity (Table 5.2) based on movement abilities and limitations (Palisano et al. 2000).

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Walks without limitations</td>
</tr>
<tr>
<td>II</td>
<td>Walks with limitations</td>
</tr>
<tr>
<td>III</td>
<td>Walks using a hand-held mobility device</td>
</tr>
<tr>
<td>IV</td>
<td>Self-mobility with limitations; may use powered mobility</td>
</tr>
<tr>
<td>V</td>
<td>Transported in a manual wheelchair</td>
</tr>
</tbody>
</table>

Table 5.2 The Gross Motor Function Classification System

Classification of children with CP into a GMFCS level is based on the child’s self-initiated movements and functional mobility as observed or reported by clinicians or parents. The GMFCS takes into consideration typical performance in home, school and community settings, rather than best capacity. The scale was designed primarily to help clinicians prognosticate about the motor function of individuals with CP. The initial GMFCS consisted of four age bands with descriptors for children between 0 to 2 years, 2 to 4 years, 4 to 6 years, and 6 to 12 years of age. Children at Level I are relatively capable. By the time they reach 6 to 12 years old, they can walk without any limitations and can run and jump to some extent, with difficulties arising only with balance, speed and coordination. At the other end of the scale, children at Level V will never achieve self-mobility unless they can learn to use a powered wheelchair with extensive adaptations. Very recently the GMFCS expanded to include an age band for 12 to 18 years of age (Palisano et al. 2008), which emphasizes the concepts inherent in the World Health Organization’s International Classification of Functioning (ICF), Disability and Health (Rosenbaum et al. 2008a).

The GMFCS has been used internationally for clinical, research and administrative purposes. It is considered to be one of the most important scales for the measurement of function in CP (Palisano et al. 2008; Rosenbaum et al. 2008b).
addition, the GMFCS is stable and can predict a child’s ambulatory status after two years of age (Palisano et al. 2006).

5.6 Clinical Features of Cerebral Palsy

CP is a wide-ranging disability that can manifest in a myriad of ways and to varying degrees depending on the size, location and timing of the lesion (Mayston 2001). This section discusses these features caused by the underlying brain insult in CP and the sequelae of these impairments on other areas of body function.

5.6.1 Postural Tone

Pathology in the central nervous system (CNS) impairs the coordination of posture and movement due to disordered muscle tone that results in stereotyped movement patterns, in turn producing atypical interactions with other bodily systems (Howle 2005; Mantovani 2007; Shumway-Cook and Woollacott 2012). Examples of significant abnormal posturing caused by tonal abnormalities include head lag, poor head control, adducted (cortical) thumbs, hyperextension of trunk (arching), opisthotonus (extended/arched position), and hyperextension and adduction (scissoring) of lower extremities (Bennett 1999; Roberts et al. 2004).

There is also persistence of primitive reflexes which causes changes in muscle tone. Abnormalities of postural tone and reflexes are frequently associated with underlying functional movement limitations for children with CP. Delays in the development of normal postural tone and reflexes can have a profound effect on the motor development and experiences of a child with CP. Persistence of primitive reflexes can limit the acquisition of skills such as rolling, reaching, and eating solid food. Delay in the development of posture reflexes can result in the inability to roll, sit up or crawl. A lack of stimuli and reinforcement from individuals and things in the environment, which can be a powerful motivating force, can lead a child with persistent developmental reflexes to become dependent and passive in interacting with the world (Ratliffe 1998). This can further limit the child's ability to learn and socialize. For example, the persistence of the tonic labyrinthine reflex (TLR) limits
the ability to come up to a sitting position, to lift the head to begin rolling and to use the arms and the legs functionally in the supine position. When the body is prone, the response is one of total body flexion where the arms and legs tend to be flexed under the body, and the head is flexed downward (Ratliffe 1998).

5.6.2 Motor/Sensory Deficits

The primary motor impairments of CP are the result of an upper motor neurone lesion leading to weakness, contracture, lack of co-ordination, altered sensation and balance, and associated reactions (Rosenbaum et al. 2007). Although CP itself is non-progressive, progressive motor impairment is a feature which often becomes more noticeable during periods of growth and development (Graham and Selber 2003). As children with CP grow and mature, they tend to develop increasingly abnormal movement along with accompanying increases in spasticity and contracture. These changes lead in turn to a general poverty of movement as a result of muscular atrophy, disuse and stretch weakness (Shepherd 1995). Long term musculoskeletal changes can be seen into adulthood with restricted muscle length causing bony abnormality and joint instability resulting in subluxation and dislocation. In addition, cartilage damage, which occurs through altered compression and immobility, results in osteoporotic changes and painful arthritis (Wright and Wallman 2011).

Hip subluxation/dislocation and scoliosis are frequently seen in children with CP, particularly in children on the more severe end of the CP spectrum (Rosenbaum et al. 2007). Hip dislocation is present in 30% to 60% of children with CP who have not walked independently for 5 years (Pountney and Green 2006).

Scoliosis frequently develops in children with CP and is thought to be caused by an underlying neurologic impairment leading to muscle imbalance. Prevalence of scoliosis in individuals with CP ranges from 15% to 61% and increases with age and GMFCS level (Morrell et al. 2002). It is estimated that approximately 72% - 90% of all children with GMFCS IV-V CP will develop scoliosis compared to 1% -2% for idiopathic scoliosis in the general population (Koop 2009). Scoliosis in children with CP can often be severe and progressive leading to decreased sitting tolerance, pain
from impingement of the pelvis against the thoracic wall, and possible cardiopulmonary complications from thoracic compression (Koop 2009).

Pain is also a common feature in children with CP, the prevalence of which increases with age (Parkinson et al. 2010; Tüzün et al. 2010). The percentage of individuals with CP who reported pain in studies has ranged from 67% to 84% (Murphy et al. 1995; Schwartz et al. 1999). Although discomfort has been reported to be experienced in almost all joints, as well as in the stomach and head, the most common sites are in the weight bearing joints of the hip, knee, ankle, lumbar spine, and cervical spine (Murphy et al. 1995; Schwartz et al. 1999).

Children with damage to the motor cortex can also sustain damage to the sensory cortex, which is in close proximity to the motor cortex. Along with specific sensory deficits such as a poor stereo-gnosis or temperature sensation, children with CP may have poor integration of their sensory systems. This problem can manifest itself in several ways. For example, the child may be hypersensitive to sensory input and respond by withdrawing from light touch or cold. The child may also have poor organization of movements, speech, and behaviours caused by poor integration of sensory stimuli, which is unrelated to motor deficits (Ratliffe 1998).

Another common feature is a tactile processing deficit which may be the direct result of injury to an area in the central nervous system (Cooper et al. 1995; Krumlinde-Sundholm and Eliasson 2002). Studies focusing on somatosensory deficits in children with CP concluded that the tactile deficits in the hands are more common in children with spasticity than in children with athetosis (Yekutiel et al. 1994). Tactile processing deficits are common in children with hemiplegia and can affect them bilaterally (Cooper et al. 1995). These tactile impairments are linked to deficits in grasping and anticipatory control of the involved hand and adaptation of fingertip forces during grip-lift tasks (Gordon et al. 1999; Gordon and Duff 1999a; Gordon Duff 1999b).
5.6.3 Impacts on Gross Motor Skills

Functional limitation is one of the major impairments of children with CP, which is present throughout the lifespan and impacts normal developmental and aging processes (Damiano et al. 2009).

There is significant evidence that children with CP have gross motor functional limitations and difficulties with activities such as sitting, walking, dressing, playing or interacting with the environment (Bower and McClellan 1994; Butler and Darrah 2001; Damiano et al. 2009). Self-care will also be affected by the severity of CP and the gross motor abilities of the child. This results in most of the children being dependent on a caregiver for basic activities of daily living (Mobarak et al. 2000).

The functional abilities of children and youth with CP vary considerably, because of the heterogeneous nature of the condition. However, there are associations between impairment type and severity and activity limitations and participation restrictions (Beckung and Hagberg 2002; Himmelmann et al. 2006). A Swedish epidemiological study of children with CP described the nature of impairments in relation to the GMFCS classification system. Himmelmann et al. (2006) reported that 32% to 41% of the children who were classified as GMFCS I were able to walk without restrictions but had limitations in advanced gross motor skills. Nineteen to 29% were classified as GMFCS II and were walking without assistive devices, but had limitations walking outdoors and in the community. Eight to 14% were children classified GMFCS III walking with an assistive device and who had limitations walking outdoors and in the community. There were 11-15% of children classified as GMFCS IV, who had self-mobility limitations requiring the use of powered mobility outdoors and in the community. Sixteen percent were children classified as GMFCS V with severely limited self-mobility despite with the use of assistive technology (Himmelmann et al. 2006).

5.6.4 Impacts on Fine Motor Skills

One of the most salient symptoms found in CP is the reduced ability to use one or both hands to manipulate objects and to perform fine motor movements. Upper limb impairment varies depending on the severity and type of abnormal muscle tone or
coordination, which may occur separately or in combination (Manske 1990). For example upper limb impairment in dyskinetic CP (dystonia or athetosis) manifests as involuntary, uncontrolled, recurring, occasionally stereotyped movements (SCPE 2000). This results in the children using a mass grasp to grasp an object. Children with CP take longer to develop isolated finger movements and as a result struggle to manipulate objects (Charles 2008). They also struggle to produce an appropriate grip force when holding objects, which also impacts their ability to manipulate objects and causes tasks such as doing buttons, a zip or picking up small objects to be very difficult (Gordon et al. 1999a). They also have difficulty with reach in that they are unable to accurately control the speed and velocity of the movement toward the object and therefore either move too quickly or too slowly (Charles 2008; Levin and Sveistrup 2008). Children with CP who still have a primitive hand grasp are often unable to release objects as they do not have active extension of the fingers and consequently objects have to be pulled out of the hand or there is a need to use another object to assist with release as seen in infants (Eliasson and Gordon 2000; Exner 2001; Charles 2008).

Moreover, fine motor impairments can lead to difficulties in fine motor tasks and impact writing and drawing, self-care activities such as eating, dressing, grooming and toileting, and play (Pierce and McWilliam 1993; Exner 2001).

5.6.5 Posture

Most often, CP affects motor control of the trunk and limbs resulting in an impaired postural stability. Children with CP often exhibit impaired postural control resulting from both musculoskeletal deformities (which can create an abnormal base of support) and impaired postural control (Gormley 2001). Impaired stability may affect numerous areas of social and physical development in this population (Hadders-Algra et al. 1999; Shumway-Cook et al. 2003). Bleck (1994) has suggested that developmental delays in the acquisition of motor skills, such as independent standing or walking, are due to poor balance control in children with CP.

Woollacott and Shumway-Cook (2005) reviewed the research on posture and balance in children with spastic diplegia and hemiplegia. They found that children
with CP had diminished ability to recover balance secondary to inappropriate muscle sequencing and decreased trunk muscle activity; increased agonist/antagonist co-activation; and delayed in ankle muscle responses.

5.7 Associated Problems with CP features

Every child with CP will have associated impairments, which may differ depending on the severity of the injury to, and the location of, the lesions in the brain (Fung et al. 2002; Koman et al. 2004; Nordmark et al. 2001). The most common associated problems with CP are presented below.

5.7.1 Communication Difficulties

Communication problems may stem from motor, intellectual and/or sensory processing deficits (Pennington 2008). Recent data from a large population-based sample in Europe indicate that 60% of children with CP have some type of communication problem (Bax et al. 2006). Dysarthria is the most common form of communication disorder (Pennington 2008). Difficulties are more often reported in children with dyskinetic than spastic types of CP (Bax et al. 2006; Odding et al. 2006). In children with spastic type CP, difficulties are more frequently observed in children with wider distributions of motor impairment (Bax et al. 2006; Odding et al. 2006). However, associations between speech disorder and motor impairment distribution are not entirely linear nor are they clear cut (Pennington 2008). For children with CP, consequences of experiencing delayed language development may include a lack of confidence, difficulty interacting with their world and reduced world experience (Pennington 2008).

5.7.2 Cognitive Difficulties

This area is of particular concern when carrying out research with children with CP. Self-reporting of participation may be affected by any cognitive or psychological impairment that affects the individual’s ability to understand the purpose of research, to understand the questions asked and provide answers, and the ability to attend to tasks necessary for data collection.
Children with CP also present intellectual disability in 60% to 72% of cases, which is the main cause of learning disorders (Singhi et al. 2002; Sankar and Mundkur 2005). The severity of intellectual disability often correlates with the extent of motor handicap, particularly in children with spastic CP. However, there is substantial variability in cognitive ability among affected individuals. Children with spastic quadriplegia are typically the most severely affected, while cognitive function usually is less impaired with dyskinetic CP that is mainly athetoid (Novak et al. 2012).

5.7.3 Vision

This group of children also have an increased risk of visual impairment. Preterm infants are particularly considered to be at increased risk for visual impairment, including retinopathy of prematurity, myopia, strabismus, glaucoma, and amblyopia (Miller and Cala 1989; Novak et al. 2012). If not diagnosed and managed early, visual deficits can interfere with developmental progress and rehabilitation. Strabismus can lead to permanent monocular vision loss (amblyopia) (Novak et al. 2012).

Himmelmann et al (2006) investigated severe visual impairment (defined as functional blindness or an acuity after correction of refraction errors of no more than 0.3 (20/60) in the better eye). Results indicated that this condition was present in 19% of children with CP. Approximately 7-9% of children with spastic CP have severe visual function disorders, defined as retinoschiasomatic and visual recognition disorders (Himmelmann et al. 2006). These disorders are frequently referred to as cortical or cerebral visual impairment and are comprised of reduced visual acuity, visual field deficits, and difficulties in visual recognition. Oculomotor disorders and strabismus are also common and add to the visual impairment. About 50% of children with CP have milder visual defects (Brizzolara et al. 2010; Guzzetta et al. 2010). In general, the likelihood of severe visual impairments increases with increasing motor impairment (Himmelmann et al. 2006; Ghasia et al. 2008; Shevell et al. 2009).
5.7.4 Hearing

Hearing impairment occurs in 10-20% of children with CP and about 5% are deaf (Novak et al. 2012). This is most common in those with very low birthweight or severe hypoxic-ischemic insults. In a study of 75 children with spastic CP, brainstem auditory evoked potentials were abnormal in 23% (Zafetriou et al. 2000). Sensorineural hearing loss is a feature of CP caused by kernicterus, which also includes choreoathetosis. Impaired stereognosia may increase activity limitation in the task of handling objects. Uvebrant (1988) suggested that it was present on the affected side in 44% of children with unilateral CP.

5.7.5 Emotional / Behaviour Difficulties

Children with CP have more emotional and behavioural difficulties than do children of the general population (Parkes et al. 2008; Sigurdardottir et al. 2010). A population prevalence of significant emotional and behavioural problems in children 8-12 years old has been estimated to be 26% (Parkes et al. 2008). Other studies have shown that levels of behavioural problems are greater in preschool children (Sigurdardottir et al. 2010) and in school age children (Brossard-Racine et al. 2012) but tend to diminish during adolescence (Sipal et al. 2010). Carlsson et al. (2008) concluded that mental health problems are common in children with CP and even more common when epilepsy is present.

Children with CP have been found to display a diverse set of emotional and behavioural problems including attention difficulties, withdrawal, aggressive behaviour, and symptoms of anxiety and depression (Sigurdardottir et al. 2010). Adolescents with CP have a less positive body image than their non-disabled counterparts (Hammar et al. 2009). The emotional functioning of children and adolescents with CP, specifically their sense of self-esteem, may be somewhat lower than their peers who do not have a disability. However, variable results from studies examining self-esteem among children with CP suggest that lowered self-esteem cannot be considered a universal trait for this group (Shields et al. 2006). A review of six studies by Shields et al (2006) identified teenage girls as being most at risk of
self-esteem issues, particularly regarding their physical appearance and social acceptance.

5.7.6 Epilepsy

Epilepsy occurs in 25 – 45% of patients with CP (Beckung and Hagberg 2002; Novak et al. 2012). Seizures are most common in patients with spastic quadriplegia and acquired hemiplegia, and less common in mild symmetric spastic diplegia and CP that is mainly athetoid (Novak et al. 2012). The onset of seizures is typically during the first two years of life. Partial seizures with secondary generalization are the most common form. Infantile spasms occur in some infants, particularly those with microcephaly and spastic quadriplegic or atonic CP (Aicardi 1990; Hadjipanayis et al. 1997). Further, children with cognitive impairment had a higher frequency of epilepsy than those without cognitive impairment (Carlsson et al. 2003). The seizure disorder itself may cause further motor impairment over time (Bax et al. 2005).

5.8 Management of Cerebral Palsy

Ideally the management of children with CP should involve: early diagnosis and comprehensive team evaluation and holistic management using a multidisciplinary approach (Papavasiliou 2009). The types of treatment for patients with CP depend on the patient's specific symptoms and range from physical therapy to medication use and surgery (Damiano et al. 2009). The goals of medical and therapeutic services for children with CP are to maximize the child's functional potential and to prevent secondary complications of the CP (Rosenbaum2003)

In the following section a detailed discussion will outline a wide variety of treatment options for children with CP. The discussion will be divided into two sections, medical and surgical and therapeutic management.
5.8.1 Medical and Surgical Management

5.8.1.1 Oral Medications

Pharmacological interventions are frequently employed for the management of symptoms, such as spasticity, seen in children with CP. A variety of oral medications have been proven beneficial specifically for the treatment of spasticity by causing a decrease in excitability of spinal reflexes. Benzodiazepines, dantrolene, and baclofen have been used in an attempt to limit drooling, reduced unwanted involuntary movement and treat seizures (Montané et al. 2004).

5.8.1.2 Botulinum toxin

Injection of botulinum toxin type A (BTX- A) is now commonly administered for spasticity management and is often used before surgery is indicated (Mayston 2012). It has the advantage of being reversible, can target specific muscles, and it can be a useful indicator for determining appropriateness of surgery (Mayston 2012). The use of BTX- A is made on an individual basis (Mayston 2012) and is important to combine these injections with physiotherapy to maximize the effect on range of movement and child's motor function, activity and participation (Scholtes et al. 2006; Desloovere et al. 2007; Scholtes et al. 2007). Naumann et al. (2006) reviewed the safety and the efficacy of BTX- A in long term use in adults and found no adverse effects. However the long term effects of its use in very young children are unknown (Barrett 2011).

5.8.1.3 Intrathecal Baclofen Pump

Another intervention for spasticity and muscle spasm is intrathecal baclofen, which has a generalized effect (Butler and Campbell 2000; Motta et al. 2007; Pin et al. 2011). However, this treatment is generally restricted to patients with severe spasticity that is not responsive to other measures (Brennan and Whittle 2008). Children treated with intrathecal baclofen had reduced tone and spasms and improved perceived comfort and ease of nursing care (Morton et al. 2011; Pin et al. 2011b).
5.8.1.4 Selective Dorsal Rhizotomy

Selective dorsal rhizotomy (SDR) is a surgical procedure that selectively divides parts of the dorsal lumbosacral roots of the spinal cord (Patrick et al. 2001). The long term effects are unknown and the time taken to rehabilitation after this procedure is at least one year. McLaughlin et al. (2002) conducted a meta-analysis to evaluate outcomes of three randomized controlled trials of SDR, including SDR with physiotherapy compared with physiotherapy alone. Ninety children with spastic diplegia who were primarily ambulatory were compared. The findings suggested that spasticity at nine to 12 months was significantly less in the combined treatment compared to physiotherapy alone. The SDR group had a modest, but significant, improvement in function (McLaughlin et al. 2002b).

5.8.1.5 Orthopedic Surgery

Complications such as joint contractures, bone and joint deformities and scoliosis hinder the basic functions of the child's movement, including sitting and walking. Surgical management of these complications includes musculotendinous or tendon lengthening, tendon transfers osteotomies and arthrodesis (Damiano et al. 2009).

These surgeries are usually performed on children between the ages of 5-25 years old. Some of these surgeries are done for prophylactic reasons before the child experiences secondary complications related to the orthopaedic deformity, while other surgeries are performed after the child begins to experience complications, for example pain and difficulty sitting (McGinley et al. 2012a).

There have been a number of studies undertaken to determine the outcome of different types of surgical interventions at different ages (Abel et al. 1999; Saraph et al. 2001; Gough et al. 2004; Kondo et al. 2004; Rodda et al. 2006; Dreher et al. 2012; Firth et al. 2013; Rutz et al. 2013). These studies have described positive effects on gait and posture. However, the evidence base is limited by the lack of randomized clinical trials, especially when compared with other invasive interventions such as selective dorsal rhizotomy (McGinley et al. 2012b).
5.8.2 Physiotherapy Management

Physiotherapy often constitutes a major part of the team approach in the management of CP. The aim of physiotherapy is to establish, promote, and maintain physical, psychological and social well-being (Scrutton et al. 2004). However, the evidence is equivocal and there is little or no evidence to support the effectiveness of any particular physiotherapy approach, nor is there evidence to demonstrate superiority of one approach over another (Mayston 2005).

Table 5.3 lists some of the most common physiotherapy and physiotherapy-related approaches to the management of CP described in the literature during the past few decades (Siebes et al. 2002; Rosenbaum 2003; Scrutton et al. 2004).

- Bobath/Neurodevelopmental Therapy (NDT)
- Conductive Education
- Constrained Induced movement therapy
- Sensory Integration
- Adeli Suit
- Biofeedback
- Electrical Stimulation
- Strength training
- Movement Opportunities Via Education (MOVE)
- Patterning (doman-delacato)
- Strength Training
- Vojta
- Treadmill Training
- Hippotherapy
- Aquatherapy
- Virtual Reality
- Alternative Therapies (e.g. hyperbaric oxygen therapy, acupuncture, and osteocraniosacral therapy)

Table 5.3 Therapeutic approaches to the management of CP.

5.8.2.1 Bobath / Neurodevelopmental Treatment (NDT)

The Bobath Approach or NDT is a popular traditional method of reducing abnormal patterns of movement and posture and promoting healthy ones in order to gain maximal functional independence (Papavasiliou 2009). While Bobath/ NDT made
an enormous contribution to the progress of CP management, there is no robust evidence to support its efficacy (Butler and Darrah 2001; Mayston 2008) and no clear evidence exists to prove the superiority of NDT over other techniques (Fetters and Kluzik 1996; Novak et al. 2013).

Nevertheless, three systematic reviews have been conducted investigating traditional NDT (Brown and Burns 2001; Butler and Darrah 2001; Martin et al. 2010). Of the 18 studies, 15 measured efficacy and three measured optimal dose. Of the 15 studies measuring NDT efficacy, 12 trials (studying 674 children) found no statistically favourable benefits from NDT. The trials were also of varying quality (high, moderate, and low). Three trials (studying 38 children) showed improvements in body structures and functions such as gait parameters, spirometry, and milestone acquisition (Novak et al. 2013). The three favourable trials were all at high risk of bias due to small sample sizes (n<16) and extremely low methodological quality such as a lack of blinding, intention-to-treat analysis, and concealed allocation (Novak et al. 2013). In the three NDT dosing RCTs, two studies (studying 96 children) found no difference between intense or regular NDT, whereas one more recent study, by Tsorlakis et al. (2004), showed favourable outcomes from higher-intensity NDT over lower-intensity NDT.

5.8.2 2 Conductive Education

Conductive education (CE) is a system of education which encompasses motor development and aims to engage children in active learning (Hari and Tilleman 1984). The concepts underpinning this approach are based on the principles of good pedagogy that are unique to CE (Mayston 2012). The theory underlying CE is that there is value in working with children in groups. The facilitation of children's activities by inviting them to say what they are doing and do what they are saying promotes learning (Bourke-taylor et al. 2007). However, there is no evidence underpinning this philosophy nor that CE produces superior outcomes to other approaches (Darrah et al. 2004; Odman and Oberg 2005; Tuersley-Dixon and Frederickson 2010).
5.8.2.3 Constraint-Induced Movement Therapy

This approach has recently emerged and is considered to improve the use of affected upper extremities in a child with hemiplegic CP. The normally functioning or stronger upper extremity is immobilized for various durations in order to force the use of the affected or weaker upper extremity over time (Taub et al. 2004; Eliasson et al. 2005; Gordon et al. 2005; Naylor and Bower 2005; Aarts et al. 2010; Wallen et al. 2011).

A recent review involving expert consensus showed that introduction of constraint-induced movement therapy (CIMT) for children with unilateral CP has led to significant advances in the knowledge of upper limb intervention. It has clearly shown that manual ability improves after training (Eliasson et al. 2014). However, the superiority of CIMT over other approaches and the dosage of training was unclear (Eliasson et al. 2014).

5.8.2.4 Strengthening Exercise

Muscle strength and resistance training have been widely used as therapeutic interventions for increasing muscle strength and functional improvement (Damiano et al. 1995; Dodd et al. 2002; Engsberg et al. 2006; Unger et al. 2006). This type of intervention may be more appropriate for adolescents and young adults with CP in whom there are no concerns about the developing skeletal system (Faigenbaum and Myer 2010; Mayston 2012). Recently a systematic review focussed on strengthening exercises as an intervention to improve function for children with CP reported that strengthening exercises, in a variety of settings and forms, can improve functional activities including moving from sitting to standing, standing, walking, running and jumping (Berridge et al. 2011).

5.8.2.5 Horseback Riding Therapy/ Hippotherapy

Hippotherapy is an individual therapy which proposes that the horses’ gait provides a marked, soft, rhythmic and repetitive movement similar to the mechanics of the human gait (Winchester et al. 2002). The warmth and rhythmic movements of the horse have been speculated to reduce abnormally high muscle tone and promote relaxation in children with CP (Miller 2007; Zadnikar and Kastrin 2011).
There is a growing body of knowledge demonstrating the efficacy of horseback riding used as therapy to improve muscle tone, balance and postural control gross motor function in children with CP (Benda et al. 2003; Casady and Nichols-Larsen 2004; Sterba 2007; Zadnikar and Kastrin 2011; Whalen and Case-Smith 2012). It also contributes to psychological well-being in areas such as self-confidence, self-esteem, motivation, attention span, spatial awareness, concentration, and ability to speak (Quint and Tboney 1998; Miller 2007; Zadnikar and Kastrin 2011).

5.8.2.6 Electrical stimulation

Electrical stimulation has been used in an effort to increase muscle strength in children with CP. Several randomized trials have failed to show clinically significant enhancement in muscle strength or function, although the numbers are small in these studies (Dali et al. 2002; van der Linden et al. 2003; Kerr et al. 2006). Two systematic reviews suggest modest efficacy for electrical stimulation interventions, but acknowledged the limitations of the evidence base (Kerr et al. 2004; Cauraugh et al. 2010).

5.8.2.7 Orthotics

Lower extremity orthoses are often used in the treatment of children with CP to address biomechanical limitations and joint alignment as well as to promote function (Morris et al. 2009). Orthoses are rarely used in isolation from other interventions and commonly provide an adjunct to regimens including therapy, BTX A, baclofen, orthopaedic, and neurosurgical procedures (Morris 2002).

5.9 Summary

CP is caused by irreversible brain damage, before, during or after birth and is one of the most common causes of severe disability in children. It affects the motor system and often other systems controlled by the brain. Motor impairments and associated problems with CP have various impacts in the accomplishment of activities in daily life and social roles.
Children with CP are a diverse group, with some experiencing rather mild symptoms of the condition, and others manifesting significant functional disability. These children’s care can be optimally managed by a team of multi-disciplinary professionals. The nature of the complexities of the treatment of children with CP has resulted in professionals proposing a variety of therapeutic interventions. The evidence and efficacy of only a few such interventions has been established.

The following chapter details the methodology that was adopted to conduct the present study.
Chapter 6: Research Methodology

6.1 Introduction

In order to understand the methods of this research, it is important first to address the theory, to illustrate where the research places itself and the stance it adopts. This chapter describes the methodology which underpinned the research design of this study. Specifically, it discusses my role as the researcher and the epistemological and ontological perspective as they relate to a critical ethnography being grounded by/in critical realism.

The chapter then describes the rationale for selecting critical ethnography as the most appropriate qualitative methodology to answer the research questions. The final part of this chapter explores the issue of trustworthiness and qualitative research.

6.2 Defining my Ontological, Epistemological, Methodological and Method Positions

Methodology is the overreaching approach to research and encompasses both philosophy and method (Figure 6.1). Choosing a methodology means selecting from alternative philosophical or theoretical positions, and deciding what research methods (procedures to collect and analyse data) to use (Finlay 2006).

Choosing particular philosophies usually implies the use of particular methods, and vice versa (Finlay 2006). The theoretical basis of a research project impacts directly upon the research design and ultimately underpins the validity or credibility and trustworthiness of claims presented in research conclusions.
Guba and Lincoln (1994, p. 108) stated that the basic assumptions that define a research paradigm can be drawn from the response to three fundamental questions:

- The Ontological questions. What are the form and nature of reality and, therefore, what is there that can be known about it?
- The Epistemological questions. What is the nature of the relationship between the knower and what can be known?
- The Methodological questions. How can the inquirer go about finding out what they believe can be known?

Therefore, applying this to this research study, the ontological, epistemological and methodological questions are as follows in table 6.1.
<table>
<thead>
<tr>
<th>Ontology</th>
<th>What is the nature of disability?</th>
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<tr>
<td></td>
<td>How does the disability exist?</td>
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<td>What is the reality of being disabled?</td>
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<tr>
<td>Epistemology</td>
<td>What causes disability?</td>
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<tr>
<td>Methodology</td>
<td>What does it feel like to be disabled?</td>
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Table 6.1 Ontological, epistemological and methodological questions.

**6.2.1 Ontology**

The ontological basis of research refers to the researcher's overarching philosophical views about the nature of 'existence' and 'reality' (Robson 2002). Bryman (2012) refers to two opposing ontological perspectives: 'objectivism' and 'constructivism'. 'Objectivism' refers to the philosophical belief that 'existence' and 'reality' are concrete and truthful concepts (Figure 6.2). In this respect, what we perceive as 'reality' has observable and measurable traits. Conversely, 'constructivism' argues that 'existence' and 'reality' consist of fluid and mutable constructs, and that there are no concrete 'truths'. Therefore, phenomena are not quantitatively measurable and 'reality' is constructed by individuals.

![Ontology Diagram](image)

Figure 6.2 Ontology and epistemology (adopted from Weed 2009).
In relation to this research, as Blaikie (2009) outlines, ontology explores claims about social reality. The fundamental question is to what degree social reality is established within structures, what is the nature of such structures, and how do people perceive and respond to such structures (Kerr 2003). This research adopted a critical realist view, believing that an external reality exists independently of our beliefs and understanding, but that we come to know our reality through the human mind and socially constructed meanings within our social worlds (Snape and Spencer 2003). A critical realist position emphasises that the researcher should be able to look further than people’s meanings, experiences and subjective understandings to include elements of structure. According to Layder (2006), structures are set of rules, systems and processes established to deal with actions; these actions which regularly represent the enduring conditions confronting people in their everyday lives (Layder 1998).

My own way of knowing the world or my ontological standpoint, naturally stems from my formative years, my cultural and life experiences. My view on being human in a changing world has developed through an integration of theory and practice, reflection and critique. My cultural traditions demand critique rather than an unquestioning acceptance of information, although this critical view of the world has come later in life. In contrast, much of my early education was based very much on a one-way provision of information that was to be accepted unquestioningly. However, I also recognise that the ontological positions of others, including participants in the study, may or may not accord with mine.

It is also important to consider epistemological issues early in a study that includes participants. If epistemology is concerned with ways of knowing, it must be acknowledged that my own cultural traditions privilege certain ways of knowing above others. Participants’ traditions place great emphasis on evidence or proof to justify ways of knowing. What is considered and accepted as evidence however, is not universal.
6.2.2 Epistemology

The epistemological position moves away from the wider concept of 'existence' and 'reality', and moves towards the researcher's beliefs about the nature of knowledge and how it can be acquired (Snape and Spencer 2003). Epistemology, therefore, "concerns the question of what is (or should be) regarded as acceptable knowledge in a discipline" (Bryman 2012). The epistemological position of a piece of research tends to fall within two main epistemological stances (Figure 5.2). Positivism holds that methods of the natural sciences are appropriate for social enquiry because human behaviour is governed by law-like regularities, and it is possible to carry out independent, objective and value-free social research. The opposing view, known as interpretivism, claims that natural science methods are not appropriate for social investigation because the social world is not governed by regularities that hold law-like properties (Snape and Spencer 2003).

The positivist assumption has been criticised by Maykut and Morehouse (1994). They explain that the world is complex, and that multiple social realities and subjectivity do exist. They also stressed that human beings are surrounded by social reality, which is difficult to measure in a statistical way (Maykut and Morehouse 1994). In social research, interaction happens between the researcher and the research study participants, with that interaction influencing the study findings and, therefore, the researcher not being objective as understood by quantitative researchers (Hammersley and Atkinson 2007; Silverman 2013). The introduction of approaches which seek to be somewhere in between these positions also includes the rise of post-positivism. Many researchers within the positivist tradition have now moved into a post-positivist standpoint, rejecting some of the more absolutist tendencies of positivism but maintaining some of its core criteria (Creswell 2003).

Post-positivists believe that every individual is unique, and that one needs to talk, listen, watch, and participate with them in their own natural setting in order for them to be understood (Mason 2002). Post-positivist enquiry questions assumptions that there are objective truths that can be determined by research, and that knowledge can be impersonal, rational and value-neutral (Neuman 2000). Post-positivist research allows that epistemology is itself culturally specific, historically located
and value-laden” (Usher et al. 1997, p. 176). Thus, post-positivist enquiry focuses on the ideas that social realities are constructed, and that social processes can only be interpreted by research, not discovered.

Since it acknowledges that epistemology is culture, value and history-specific, it also allows (actually, expects) me to be open about my theoretical positioning in relation to the concepts with which the research is concerned; this paradigm acknowledges that the researcher can never be “hidden” (Neuman 2000). It also allows me to focus on the things which interest me, the richly diverse experiences of my participants and legitimates my preference for a small scale, in-depth study, since a larger-scale study would not by virtue of its size throw up more reliable “truths”. The post-positivist frame therefore is not only suggested by my personal orientation towards the research process. It also enables me to develop methods that are in keeping with this orientation. By gathering descriptive data and presenting it in participants’ own words, I can try to capture their experiences as closely as possible and locate them as significant individuals at the centre of the research process (Sarantakos 2013).

As post-positivism recognises that all observations are fallible and that there is no one fixed and definitive truth, it positions the researcher as someone who is prepared to learn throughout the process of research rather than someone who is testing a hypothesis (Ryan 2006). Post-positivist enquiry therefore fits the particular focus of this research, which deals with participants’ memories and interpretations of events that I, as the researcher, cannot observe.

6.3 Critical Realism

Critical realism was used as the underlying framework for this study and therefore guides the approach to answering the research question and interpreting the results. Since the conceptual framework of the study influences all aspects of the study, including the goals of inquiry, method, and interpretation of findings, it is important to understand the foundations of these conceptualisations.
Critical realism is a philosophical approach developed by Bhaskar (1978), which will be explained briefly here. Bhaskar's use of the word ‘realism’ stems from the fact that he asserts (in contrast to phenomenological tenets) that there is reality out there independent of our observation or thought. Moreover, Bhaskar argues that reality is not confined to things but also includes those structures that have effects upon things (Porter and Ryan 1996).

The defining feature of realism is the belief that a ‘world exists independently of our knowledge of it’ (Sayer, 2000, p.2), and the independence of objects from knowledge immediately ‘undermines any complacent assumptions about the relation between them and renders it problematic’. Therefore, as critical realism is ‘wary of simple correspondence concepts of truth’ (Sayer, 2000, p.2), it offers a rationale for critical social science, which is critical of the social practices it studies as well as of other theories (Sayer, 2000, p.18).

Critical realism is first and foremost concerned with ontology questions about what exists. As Bhaskar (1978) argues, a philosophy of reality must begin with a theory ‘of being’ (ontology) as distinct from a theory ‘of knowledge’ (epistemology). Having identified what ‘is’ or what exists, critical realism then moves to focus on questions concerning the creation of knowledge about that existence (Pearce and Frauley 2007). This is a key difference which distinguishes critical realism from other meta-theoretical positions such as positivist and hermeneutic approaches to knowledge. They both adopt epistemological approaches to knowledge, whereas for Bhaskar the purpose is to re-orientate theory towards ontology (Nairn 2012).

Critical realists propose that social structures operate at many sites and levels and that event experiences at the individual level may be the culmination of numerous, perhaps even countervailing, extra-local influences (Scambler 2001). However, complex phenomena cannot be understood fully based on direct experiences alone, and the structures exist independent of people’s knowledge of them. Consequently, one major tenet of critical realism is that reality is stratified. Bhaskar distinguishes three domains (Figure 6.3): the empirical, the actual and the real (Bhaskar 1998). When the critical realists refer to the real, they firstly note that the real is whatever exists, natural or social, regardless of whether it is an empirical object and whether
there is an adequate understanding of its nature. Secondly, the real is the realm of the social with its structures and powers, which have capacities to behave in particular ways and causal liabilities or passive powers usually susceptible to certain kinds of change (Sayer 2000). Therefore, real refers to structures and powers of objects, and the actual domain refers to what happens in reality when the powers or mechanisms of the real are activated, and events and experiences are produced (Collier 1994; Sayer 2000; Danermark et al. 2002). The empirical domain is comprised only of what we experience (directly or indirectly); however, not all events are experienced (Collier 1994), with respect to either the real or the actual though it is contingent on whether the real or actual is known (Sayer 2000, p.12). That means that experiences and observations do not necessarily give us a real picture of a phenomenon because they might not show how things are really related to each other. Thus the focus shifts from the observable phenomena to the underlying structures and mechanisms that cause or support these phenomena.

Critical realism argues that science is a social product (Sayer 1992) and makes a fundamental distinction between two dimensions of knowledge, namely, the intransitive and transitive (Bhaskar 1998; Sayer 2000; Danermark et al. 2002). From a realist perspective, science aims to understand this intransitive dimension of reality through socially produced theories (transitive) that are potentially fallible and limited. In other words, the intransitive refers to the real entities or objects of scientific knowledge that constitute the natural and social world (Outhwaite 1987). It can include and extend to all that exists (ontology) (Bhaskar 1978). The transitive includes the established facts, theories, models, paradigms, and techniques of inquiry available to a particular scientific discipline or individual (Bhaskar 1998): the epistemological (Danermark et al. 2002). Such theories, models and paradigms may compete and challenge each other; however, the world that they are about (intransitive) remains constant (Collier 1994). In other words, although our understanding and theories (transitive) of the world may change, this does not necessarily mean that the world or reality (intransitive) that they are referring to change (Sayer 2000). For example, the social and medical models of disabilities may challenge each other, while at the same time the experience of impairments (intransitive) may not change.
However, a crucial implication of this ontology is the recognition of the possibility that powers may exist that are not yet exercised and so what has happened or been known to have happened does not exhaust what could happen or have happened” (Sayer, 2000, p.12). A feature of reality is that there is an ontological gap between what we experience and understand, what really happens, and most important the deep dimension where the mechanisms are (real domain) which produce the events’ (Danermark et al. 2002, p.39). Realist ontology, therefore, has the potential to allow us to understand how we could be from that which we currently are not (oppression/controlled versus freedom) (Sayer 2000). For example, we may experience and have an understanding of disability; however, realist ontology allows us the opportunity to explore independently the concept of disability within the domain of the real and to discover the generative mechanisms that may be producing this disability (Bergin et al. 2008).

Reality is also viewed as being stratified, whereby generative mechanisms belong to different layers or strata of reality (Collier 1994). For example, strata can include the physical, biological, psychological, social and economic (Danermark et al. 2002). It is this stratified ontology that differentiates critical realism from other ontologies, in so far as they only engage the actual or the empirical domains of reality with no
recognition of an independent reality. This real domain is beyond what we experience or observe and has powers that may or may not be activated (Sayer 2000). This stratification allows new mechanisms to be created that are referred to as emergent powers (Danermark et al. 2002). In keeping with these stratified principles, two or more features of the world may combine to produce a new event or experience; however, such occurrences cannot be reduced to only their components, even though such components are necessary for their existence (Bergin et al. 2008). In the example of disability, culture and religion or family expectations may produce the experiences of mothers of children who have CP, but no single component causes or produces that experience by itself.

Furthermore, critical realists accept the possibility of complex causality, meaning that mechanisms do not always play out as the same actual events or empirically observable experiences (Bergene 2007; Clark et al. 2008; Lipscomb 2010). Social structures operate at many sites and levels, and events experienced at the individual level may be the culmination of numerous, perhaps even countervailing, extra local influences (Scambler 2001). Hence, outcomes do not take the form of strict regularities, but are manifested as semi-regular patterns or demi-regularities (Lawson 1998, p.149).

Critical realism also suggests that causality or cause and effect is complex, with many mechanisms or forces operating at the same time, some reinforcing and some contradicting or competing with each other, which will differ from context to context. Because of this, critical realism argues that an adequate explanation of human action must include the structures and cultural forces that shape but do not necessarily determine those actions. As Sayer (1992, p. 119) notes, social structures such as gender or ethnicity may exist only where people (re)construct them; however, their powers are often _irreducible_ to those people. For that reason an understanding of individuals sometimes requires a _macro regress_ to the social institutions in which they are situated, as well as a _micro regress_. Therefore, we need to explore the interplay of both when we study the social world (Danermark et al. 2002).
It is important to mention that critical realism has itself been subjected to critique from both positivists and interpretivists. Positivists argue that critical realists are open to the charge of bias in their utilisation of values of human emancipation and flourishing in the research endeavour, because the application of values in any given situation is subjective (Hammersley 2009). Critical realists respond by saying that these values underpin all research endeavours, whether acknowledged or not. Therefore, the decision needs to be as informed as possible — hence the importance of ascertaining generative mechanisms (Walsh and Evans 2014). Interpretivists challenge the idea that a layered ontology can be identified with any certainty, as any reality is provisional and contestable and, in any case, our knowledge of it is partial and subjective (Deforge and Shaw 2012). Critical realists would say that the deeper layers of ontology are real because their effects are real, and it is therefore incumbent on researchers to seek them out as comprehensively as possible, whilst acknowledging that they remain generative, rather than definitive mechanisms. Only then can change in effects at the empirical level be addressed effectively (Walsh and Evans 2014).

6.4 Justification of Philosophical Position

The philosophical position in my research is a critical realist position. The position determines the way reality is understood in this study and how it is recognized. In a critical realist approach, there is a critical view of using quantitative methods to explain phenomena, but there is also a critical view of using pure subjective assumptions to explain a given phenomenon (McEvoy and Richards 2006). But according to critical realism, subjective intentions cannot be ignored when we are trying to understand society (Bhaskar 1998). The method applied in the study uses focus group interviews, individual interviews and participant observations that give a picture of reality through subjective perceptions. The subjective perceptions are combined with analysis to see if causal powers of objects are generalisable to other contexts, for example, the influences of the cultural backgrounds on the perception of the term CP (Carspecken 1996).
Critical Realism recognises that different experiences of reality can and do exist (Bhaskar 1989; Collier 1994; Robson 2002). This recognition was central to this study, as it sought to explore the effects of culture on children with cerebral palsy from the perspectives of mothers and children in terms of cause and effect. This meant uncovering the complex interrelationships between children, mothers and the Saudi culture in which the study takes place. The uncovering of reality in a particular and defined context is a key aim of the Critical Realist approach. The overall goal of critical realism is to uncover structured relations that generate patterns of actions and interactions. One such set of those structured relations, like gender or ethnicity, is disability.

The critical realist approach was particularly applicable to this study. Bhaskar argues that critical realist research is potentially emancipatory, since it involves looking beneath the surface to understand the social mechanisms which result in needs not being met (Collier 1994). To adopt a critical position is not just to acknowledge researcher subjectivity but also to incorporate it into the research process by using the researcher's subjective position reflexively. The critical position enables research to move beyond knowledge-generation, since it includes the critique of existing ideological or institutional operations with a view to changing the world. Critical social research differs from the interpretive frame rather more in the types of questions asked and the purpose of the research than in the techniques used (Neuman 2000). The intention in conducting this study was to empower children with CP and their mothers and allow their voices to be heard. A critical researcher, then, will be explicit about their original position and document "where their research took them as investigators and political actors" (Carspecken 1996, p. xi). However, the interpretive approach, which gives voice to the researched, is a reminder to researchers to ask how it is possible to do critical qualitative research in a way which is not only "disciplined" but also "caring" (Carspecken 1996, p. xi). Within a critical research frame, the researcher's political position becomes a central and explicit element in the design and conduct of the research.

Moreover, critical realism has also begun to emerge within the ranks of disability studies itself. The most prominent scholars are Tom Shakespeare and Nick Watson. This approach differs from those of Williams (1999) and Bury (2000), as it does not
dismiss the disability rights movement but looks for a theoretical standpoint in order to enhance current disability studies thinking:

→ find the critical realist perspective to be the most helpful and straightforward way of understanding the social world, because it allows for this complexity. Critical realism means acceptance of an external reality: rather than resorting to relativism or extreme constructivism, critical realism attends to the independent existence of bodies which sometimes hurt, regardless of what we may think or say about those bodies. Critical realists distinguish between ontology (what exists) and epistemology (our ideas about what exists)” (Shakespeare 2006, p.71).

It can be assumed that by adopting a critical-realist approach it is possible to recognise the embodied experience of disability along with acknowledging the importance of removing disabling barriers (Shakespeare 2004). With this in mind, disability can be understood through ontology (reality) and epistemology (knowledge).

Using this critical realist approach we can understand the phenomenon of disability in three stages. The first is the 'empirical', which relates to the social experience of living with disability. This refers to the concept of personal interaction, social constructivism and the internalisation of this syndrome. The second process refers to disability as an 'actual' biological reality relating to neurological pathways or brain differences. As Danermark (2002, p. 57) shows, this reality can occur 'independently of whether they are observed or not'. The final process refers to the 'real' and constitutes the institutionalisation of disability within powerful organisations, in this case Saudi culture and society. In order to construct a theoretical understanding of disability we cannot refer to a single area of knowledge (such as social constructivism or biological determinism), rather we must comprehend each process simultaneously (Danermark et al. 2002).

Critical realism accepts that research is value-laden and that the researcher is not objective (Neuman 2000). For this reason, critical realists account for influences of the researcher, to clarify the context in which research takes place and knowledge is
generated. Critical realism advocates research in a natural setting to make knowledge context-specific (Robson 2002). In this study I view the situation of disabled children in Saudi Arabia as a real existing problem, and I do not question the situation’s existence. Furthermore, I seek to understand how this problem is approached from the children’s and mothers’ perspectives and how cultural and structural factors influence them. The subjective perceptions of the children and mothers as well as the objective existing structural and cultural aspects combine both the objective and subjective perspectives (Sayer 2000).

6.5 Ethnographic Approach

My aim is to capture the experiences of the mothers and children conveyed in their own words, and to use their viewpoints as the basis for discussion and analysis. Padgett (1998, p. 8) suggests that when the researcher seeks understanding, the qualitative methods are the most useful way to explain the respondents' position. Padgett (1998) adds that the ways in which respondents view their worlds and create meaning from their life experiences are countless and can best be explored by a qualitative approach. Williams and May (1996) suggest that the concern of qualitative research is primarily with qualities of given phenomena and less with quantities. Qualitative research encompasses a range of strategies that allow researchers to become near to the data. They are often described as being concerned with the daily actions of people and the meanings that they attach to their environments and relationships.

Additionally, as Silverman (2010) notes, qualitative approaches are particularly suitable when we seek to understand a social situation about which we have limited understanding, as was the case in this study. Therefore, I have chosen a qualitative approach in this study because this approach can be used to better understand any phenomenon about which little is known, to gain new perspectives on things about which much is already known, and also to gain in-depth information that may be difficult to convey quantitatively (Strauss and Corbin 1998). I am aware that in qualitative research, the ability to fully describe a phenomenon is an important consideration, not only from the researcher’s perspective, but also from the reader’s
perspective (Lincoln and Guba 1985). Qualitative researchers try to understand the meaning people have constructed about their world and experiences and how people make sense of their experiences. They are interested in understanding people’s experience in context and see the actual settings as a direct source of rich data. In qualitative research, the participant’s perspectives define what is real (Patton 2002; Denzin and Lincoln 2011).

Research approaches in the qualitative tradition take various forms that include ethnography, phenomenology, grounded theory, discourse analysis, narrative analysis, feminist approaches, cooperative enquiry, case studies, repertory grid, action research, and biographical and historical approaches. Each of these methodologies holds different aims, involves different research designs, and utilises different research methods (Finlay 2006).

Other qualitative approaches were reviewed prior to commencing the study, in particular the use of grounded theory and the use of a phenomenological approach. Grounded theory involves identifying and integrating categories of meaning from data to understand a phenomenon. It is more suitable for use in explaining social processes, rather than exploring the nature of experience (Willig 2008). The grounded theory method could be used to map the categories of concepts that people use to make sense of their experiences of disability and to understand the structure of their experience (Willig 2008). However, grounded theory is geared towards the development of theory, and my aim was to allow children’s and mothers’ hidden voices to emerge, to hear their own views of their lives rather than explain their experiences. Grounded theory did not seem to fit with my research questions.

Additionally, the grounded theory approach requires a prescribed and structured method of data collection and analysis with the goal of the research being the generation of an inductively derived theory (Bowling 2002), which was not the objective of this study. Further, as Johnson and Webb (1995, p.83) have cautioned, the inflexible use of grounded theory concepts and excessive diagramming of relations between concepts can be as reductive as those survey methods which grounded theory was meant to supplant'.
Another research approach commonly used is phenomenology (Dowling 2004). This is a research approach, and also a philosophy, that focuses on the lived experience, a perception of the individual's being in the world as a mode of inquiry that seeks to derive the essence of an experience (van Manen 1990). As this approach centres on seeking understanding of the meaning of the essences of a particular human experience, it would not provide a research approach to address the study's aim of seeking a cultural understanding of the term CP. After consideration of alternative approaches, an ethnographic approach was considered to be appropriate for this study.

Ethnography has become an increasingly popular methodological approach in health-related research, along with other types of qualitative methods (Hammersley and Atkinson 2007; Marvasti 2004). It is an approach that has been developed by anthropologists with the purpose of exploring, describing and interpreting culture, or factors that influence culture (Roberts 2009). Fetterman (2010) stated that ethnographic research is typically guided by a model based on a paradigm that embraces multicultural perspectives and accepts multiple realities. People act on their individual perceptions, and those actions have real consequences; thus, the subjective reality each individual sees is no less significant than an objectively defined and measured reality (Fetterman 2010).

Furthermore, ethnography as a research method has enabled children to be recognised as people who can be studied in their own right within the social sciences, permitting children to become seen as research participants. Ethnography is fast becoming a new orthodoxy in childhood research (James 2001, p. 245). Children are subjects and participants rather than objects within the research. James asserts that what ethnography permits is a view of children as competent interpreters of the social world (James 2001, p. 246). The study of childhood acknowledges the contribution children can make to understanding their experiences, and represents a shift in the perspective of research (James 2001, p. 246).

There are several major ethnographic approaches, including classical, systematic, interpretive, descriptive and critical ethnography (Roberts 2009). Each type of ethnography represents a different philosophical position that influences the way a
study is conducted and determines the framework for how data is collected and analysed (Streubert and Carpenter 2011). Table 6.2 provides an outline of the various characteristics.

<table>
<thead>
<tr>
<th>Classical ethnography</th>
<th>Prolonged contact with a group under study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systematic ethnography</td>
<td>Attempts to define and delineate a structure, specifically cultural structure</td>
</tr>
<tr>
<td>Interpretive ethnography</td>
<td>Attempts to discover the meanings and behaviour of social interaction</td>
</tr>
<tr>
<td>Descriptive ethnography</td>
<td>Describes what is happening</td>
</tr>
<tr>
<td>Critical ethnography</td>
<td>Emphasises the subjectivity of the researcher and focuses on power interactions</td>
</tr>
</tbody>
</table>

Table 6.2 Types of ethnography (Roberts 2009).

While ethnography in and of itself is concerned with describing the elements of a particular culture, critical ethnography has an additional goal of understanding of how and why the values, beliefs, and behaviours of a particular group are shaped, and, moreover, to influence change and/or incite action within that culture. This study intends to focus not only on the participants' perceptions of the term CP, but with applying its findings to bring about change, rendering research more relevant to national policy-making or to professional practice (Hammersley and Atkinson 2007). Therefore, the methodology for this research can be aligned with critical ethnography.

Critical ethnography, most often informed by critical theory and the critical paradigm, is an applied form of ethnography that is in search of knowledge to inform change (Creswell 2003). The traditional accounts of critical theory include Marxism, but critical realism extends and develops these. Critical theory is concerned with how social issues, including power, culture, ethnicity, class, gender, ability and sexual orientation form a socio-political system (Kincheloe and McLaren 2003), and directly or indirectly dominate people's expressions (LeCompte and
Cultural critique is the main purpose of critical ethnography (Foley and Valenzuela 2005). Thomas (1993) emphasises the point that, in essence, critical ethnography combines a focus on interpreting culture with an obligation to present the findings to enable transformation. Critical ethnography explores the culture, community and everyday circumstances of participants with the goal of seeing what is and what could be (Thomas 1993). It involves seeking not only to uncover sociocultural knowledge about a group, but also patterns suggesting social injustice. Critical ethnography has the potential to raise consciousness about the injustice, inequalities and hegemonies of social life (Korth 2002). Critical researchers share a value orientation in that they are concerned with social inequalities and direct their work towards positive social change (Carspecken 1996).

As Thomas (1993) explains, critical ethnography requires researchers to stretch their sociological imaginations and shift focus from discrete instances of phenomena to their broader social contexts. Critical ethnographers assume that the relationship between social structures and social agents involves a two-way, mutually constituting process. The enablement and constraints imposed by structural elements influence social and individual action. Such actions can, in turn, serve to maintain or transform social structures (Carspecken 1996; Kincheloe and McLaren 2005; Madison 2005; Thomas 1993)

A critical theorist believes that all are responsible for creating social conditions in which all people can live and speak freely (Allen et al. 1986). This means that the research is not only descriptive or interpretative, but that the researcher and participants are actively engaged in critical dialogue with the intent of exposing personal, cultural, and political aspects of social action (Brodkey 1987). In critical ethnography, the researcher enters the constituted field and becomes familiar with what agents already know, and have to know, to go on in daily life (Giddens 1984; Kushner and Morrow 2003). Furthermore, the study of cultures or social groups is undertaken with the intent to contribute to emancipation of the target group and
reduce repression by dominant social groups, by uncovering hidden oppressive structures through critical analysis of the data and by empowering participants, using their voices in the analysis (Carspecken 1996; Thomas 1993).

Ethnography presents its own limitations and difficulties for the researcher as an 'insider' and raises serious concerns about the researcher's objectivity (Hayano 2001). The researcher has to acknowledge his/her own prejudices and be especially aware of these. To deal with these objections it is important for the researcher to make his/her own processes and reflections as clear as possible and to use a range of research tools to 'triangulate' the methodology and check on the quality and validity of the evidence obtained (Hayano 2001; Bryman 2012).

Since the research was conducted in my work area, I collected the data as an insider. This would affect the research and its findings throughout. However, being a reflexive practitioner, I was aware that I was part of the world I researched (Berg 2004). Researchers should be 'self-conscious' and self-aware throughout their research, continually examining their assumptions (Holloway and Wheeler 2010). Reflexivity was therefore important in this research and will be considered later in the thesis.

6.6 The Rationale for Selecting Methodology

In this research study, I have chosen to use the critical ethnography proposed by Carspecken (1996) as the primary practice for inquiry for several reasons. Firstly, Carspecken's critical ethnography is essentially about the study of culture. It is therefore appropriate for me to answer the research question which is aimed at exploring the cultural aspects of the term CP based on the knowledge of children and mothers and their interpretation of their perception and experiences. It enables me to study the mothers' and children's experience in Saudi culture and to make sense of mothers' and children's actions by observing them in the context of their environment (Varcoe et al. 2003; Roberts 2009).
Secondly, critical ethnographers speak "to an audience on behalf of their subjects as a means of empowering them by giving more authority to their voice" (Thomas 1993, p. 4). It respects the individual voice and experience, while simultaneously acknowledging the inter-subjective, inter-experiential, and cultural origins of self. It involves exploration of how class, gender, power, economic policies, and socio-historical interactions impact upon marginalised segments of society. This was an important consideration when designing the study because it is more than just the study of mothers and their children; it is also about learning from them and empowering them by giving them the opportunity of having a voice, something which is not common in Middle Eastern countries, and particularly so in mothers.

Thirdly, critical ethnographers pay attention to the effect of power structures on individual subjectivity. One of the central ideas guiding critical ethnography is that "social life is constructed in contexts of power" (Noblit 2004, p. 184). Critical ethnography places importance not only on how power relations materialise in the lives of the participants that are being observed, but also on how power relations between the observer and research participants influence the practice of research activities and knowledge creation. In critical fields of research, researchers are disturbed by basic issues of social structure, power relationships and culture, and they are interested in how inequities affect human behaviour (Carspecken 1996). Critical ethnographic research raises awareness of unequal power relationships.

Fourthly, ethnography would provide an insider view of what happens in the research sites with regard to the cultural aspects of human interactions, specifically how mothers behave and how they relate to each other. Finally, by adopting a critically ethnographic approach to transforming data into text within this research, I have been able to give an account of a process of enquiry and action that I have been, and continue to be, involved in. I could set the research within a time frame and context, relating it to the mothers’ personal experiences, perspectives, and understandings of both research participants and myself.
6.7 My Role as a Researcher

Insider or Outsider

In critical ethnography, the researcher is the instrument or tool that collects and interprets the data through their personal lens of reality (Creswell 2003). There are two terms commonly used in ethnography, which are "emic" and "etic" perspectives. The "emic" perspective gives the insiders’ perceptions, and enables the researcher to uncover knowledge of why people behave in the way they do. Conversely, the "etic" is the alternative perspective and this is when the researcher attempts to make sense of what has been observed without the group’s explanations (Roberts 2009).

As most ethnographic research acknowledges that the work is carried out by a "deeply interested observer” (Ramanathan and Atkinson 1999), critical research allows the researcher's ideology and values to enter intrinsically and inseparably into the methods, interpretations and epistemology (Carspecken 1996, p. 5).

In this research I aim to use both emic and etic perspectives. I felt like an insider and part of the group because I had worked with mothers and children professionally over several years. However, after conducting the focus group and interviews, I chose to be an outsider for analysis to keep out personal judgments and biases. The idea is to keep the two voices separate — emic (insider's voice, participant’s voice) and etic (outsider's voice, researcher's voice) — as much as possible and decide whose voice will be the predominant voice in the text.

Being a paediatric physiotherapist working with children with CP over many years and also as a woman born and raised in Saudi Arabia, I am aware of the challenges facing women in Saudi Arabia towards children with disability, which assisted me in this research. This understanding was supported by Pellatt (2003) who found that characteristics of being familiar and part of the culture helped to gain acceptance by participants. However, Spradley (1980) disputed this concept, suggesting that the more familiar you are with an environment, the more trouble you will have exploring it as an ethnographer. Spradley (1980) cautioned against the use of complete participation, arguing that the less familiar you are, the more likely you are to observe inherent cultural features.
As a researcher and physiotherapist, I also have the interest in helping mothers to understand their own actions within the historical and social context, and to be prepared to challenge and transform the conditions of oppressive and inequitable moral and social practice (Simon and Dippo 1986). Acknowledging that all thought is fundamentally mediated in power relations that are socially and historically constituted, inequalities between certain groups in any society can be revealed, as well as the reasons sought for their privileged position. By helping mothers and children to understand their position in society, they then have the possibility to question and reflect on this position with the potential to change.

During the interviews and focus group, I did not make any statement that I empowered mothers and children to make changes in their perception of the CP term. I did not see myself as an activist on their behalf. I viewed myself as a person who has much to learn from these mothers’ experiences and together through understanding each other.

It was also important as a researcher that I develop an understanding of the emic perspective or the insider perception of the mothers’ and children's views in order that I can give an explanation of their feelings and experiences. This perspective is essential for the study. This is also something that is very new to me as a researcher and as a clinician. I was originally educated in a style which endorsed the medical model and gave me a positivistic way of thinking and working with patients and clients. However, through my clinical experience I realised that in order to understand the mothers' and children's perspectives, this approach was insufficient and inappropriate and I began to note my disquiet with such an approach. I have reported my reflections on my assumptions prior to commencement of the study, which will also be discussed.

The other issue that I have to consider is the nature of culture within Saudi Arabia and the cultural norms of disclosure and expression of emotion. Whilst ethnography explores emotions, feelings and cultural influences in depth, Saudi Arabia is a culture that exhibits relatively closed communication processes, whereby expression of personal feelings and emotions is not common at a relatively superficial level.
Thus, asking mothers to ‘open up’ and expose such expression is contrary to cultural norms.

Streubert and Carpenter (2011) suggest that the researcher must share their perceptions and thoughts about a research topic prior to engaging in the study. Assumptions, beliefs and values once exposed in this way can be acknowledged and challenged, although full disclosure may never be possible since many biases and ideas are not consciously known or talked about (Giddens 1984). Furthermore, as the data collection tool throughout the study, the researcher's role required honesty, which contributed to the rigour of the study (Rice and Ezzy 1999).

Throughout the research I was aware of the bias that I may have brought to the study, due to my enthusiastic interest in formative assessment and the importance I place on the quality of feedback. Holstein and Gubrium (2003) highlight the need for researchers to be aware of their position within the research process and to consider that respondents in turn might also be wondering what the researcher's position is.

6.8 Trustworthiness of the Study

The goal of qualitative research is to create an account of the method and data collection, which can stand independently so that another trained researcher could analyse the same data in the same way and come to similar conclusions (Lincoln and Guba 1985; Lietz et al. 2006). Several strategies have been identified in the literature for ensuring rigour or trustworthiness in qualitative research, including reflexivity, credibility, transferability, dependability, and confirmability (Lincoln and Guba 1985). For this research I used triangulation, transferability, reflexively, and dependability.
6.8.1 Triangulation

Triangulation has been identified as one way of obtaining rigour in qualitative research studies. Triangulation is basic in ethnography and it is the heart of ethnographic validity (Fetterman 2010). The literature identifies two advantages of using triangulation in qualitative research. The first is to enhance the validity of the study, and second is to enhance the researcher’s understanding of the phenomena being studied.

In this study, I used various triangulation methods by applying several approaches in collecting data, such as observations, focus group, interviews, and field notes (Bryman 2012). Semi-structured interviews allowed mothers and children to tell their experiences in their own words. Trustworthiness was facilitated by conducting interviews in an open manner, and creating a space for personal reflections. Furthermore, I used multiple recording devices and multiple observers including tape recorder and note-taking by the research assistant and myself, and these notes were compared after the focus group. Additionally, I developed a follow-up individual interview for the mothers, shared with them the focus group transcript, and I asked them to corroborate in what I thought and what I had found. This researcher-participant relationship enabled engagement to be taken beyond a clinical partnership to one of great depth and meaning, which facilitated researcher integrity and sincerity (Fontana and Frey 2003).

For children I used flexible interview techniques such as Talking Mats, play, and tailored questions to obtain their response. When children express their views through play, their verbal and nonverbal behaviors often reveal a story about their perspectives. However, despite having these tools, interviewers should be reflexive on how the interview is conducted because the interviewer’s attitude can influence how they ask the question and how the interviewee subsequently responds (Holstein and Gubrium 2003; Rubin and Rubin 2005).
6.8.2 Transferability

In qualitative research, transferability refers to the probability that findings have meaning to others in comparable situations and may be considered the theoretical generalisability of the findings (Bryman 2012). It is vital that the researcher provides a careful description of the phenomenon being studied and sufficient contextual information such that the reader can make a reasoned judgment about the fittingness or applicability of the study findings to other situations (Sandelowski 1993). Guba and Lincoln (1994) noted that the major technique for establishing the degree of transferability is thick description. Transferability in this study was enhanced by providing extensive and contextual information and thick description of the research findings so that readers may judge the level of fit, or fittingness, between this study and other situations. Moreover, in the study, I presented data in a number of ways, including text, tables, figures, and verbatim quotations, to assist the reader in this transferability interpretation. Providing such rich descriptions will allow the reader to judge whether the research findings might be transferable to other people in similar situations to those of the participants, while also evaluating the quality of the research. For example, the extent to which the findings of this research study are transferable to Middle Eastern mothers and children can be judged by the reader.

6.8.3 Reflexivity

Writing and reflexivity are inseparable, as it is reflexivity that gives voice to the researcher by illuminating the research process and acting as a bridge between interpretation and how meaning is expressed in text (Brewer 2000). As a result, reflexivity requires reflection on processes that influence the data. Brewer described two types of reflexivity: descriptive and analytical. Descriptive reflexivity involves reflecting on all possibilities that influence the outcome of the research, including location, researcher preconceptions, power relations in the field, and interactions between researcher and people involved. Analytical reflexivity is perhaps more difficult, as it deals with epistemology and knowledge claims requiring a form of ‘intellectual biography’ (Brewer 2000, p. 130).

Analytical reflexivity allows for the explanation of the process of data understanding and interpretation. On the other hand, descriptive reflexivity has several aspects:
how field notes were kept, how the coding, recording and organisation of data were performed, ways in which the key ideas were identified, and how the process of data analysis was performed. Analytical, however, is more intense than descriptive reflexivity. This is due to the reflection on and highlighting of the theoretical framework and methodology used in the research. This allows for the acknowledging of values and commitments that the researcher brings to the research. The researcher must identify the passion and issues she brings to the process and then allow thoughts connected to the research to be acknowledged.

In this research I adopted a reflexive approach in all stages and was taken to be both descriptive and analytical to achieve my goal of illuminating all processes to the reader. I explicitly stated the assumptions underlying the study and reflected on my personal opinion and positionality in relation to issues that came up during the interviews.

6.8.4 Dependability

Lincoln and Guba (1985) argue that the researcher should describe the process and context of the research in great detail. This enables the reader or another researcher to follow the process as well as to provide the means for them to conduct similar research (p. 316). Particular attention to details which articulated the process of this study have been presented in the thesis. The researcher clearly justifies the choice of critical ethnography as a chosen approach. Knowledge of this approach is articulated in the ways in which aspects of the study are undertaken and presented, for example, how the study question is posed, how the design was employed, and how all techniques have been justified in relation to selecting and recruiting participants, data collection and data analysis processes (Fossey et al. 2002; Shenton 2004).

6.9 Summary

This chapter has described the journey of moving towards the development of a methodology that enabled this research to take place. It contains a discussion around
the theoretical philosophy of critical research, and the rationale for adopting the critical ethnography approach. The next chapter illustrates the methods of data collection and data analysis used in this study.
Chapter 7: Research Methods

7.1 Introduction

This chapter offers a detailed description of the sequence of the research process, covering the ethical considerations relevant to the study, its setting, the recruitment process, and sampling techniques. It also explains the techniques and procedures used for collecting data. Finally, there is a discussion of Carspecken's (1996) five stages of critical ethnography, which guided the analysis.

7.2 Ethical Considerations

Ethical considerations for clinical research are laid down in the Belmont Report (1979), which identifies three fundamental principles that underlie all research involving human subjects: respect for persons, beneficence, and justice. These principles are to be applied to a research study through informed consent and the assessment of risks and benefits. As I recruited children to participate as informants in this study, I considered their status as potentially vulnerable subjects. Conducting research with children gives rise to several ethical issues, namely each child's capacity to provide informed consent, maintaining confidentiality, achieving privacy, and the power differential between child and adult (Lewis and Lindsay 2000; Punch 2002; France 2004).

These ethical issues are not unique to children and many are present when conducting research with adults. However, it has been argued that there are important differences in how they are approached with children due to children's understanding and experience of the world being different to adults, differences in how children communicate and because of the more acute unequal power relationships that exist between adult researchers and child participants (Mauthner 1997; Thomas and O’Kane 1998; Punch 2002; Kirk 2007). When participants are
disabled children, these issues are possibly heightened. These issues will be addressed in this section.

7.2.1 Participant Information and Consent

Obtaining informed consent from any research participant is one of the most critical ethical procedures in research. The ethical issue of consent has probably generated the most debate with regard to research with children (Morrow and Richards 1996; Alderson and Morrow 2004; Cocks 2006) and a large body of literature is dedicated to discussions of consent. However, Alderson (2005) notes that, despite this substantial body of literature, covert research in which children are watched or questioned without their own or their parents’ permission is still widely accepted.

Informed consent is a process of three interactions: provision of information by the researcher, the potential participant understanding the information, and then making a response to it (Cocks 2006). The interactive nature of this process makes it a two-way exchange of information, with the central feature present in all decision making of digesting information, weighing it up in light of personal values, and making and standing by a decision” (Alderson 2002).

When working with children it is usual for researchers to obtain consent from adult gatekeepers, usually the parents. However, there are ethical concerns when accessing research participants through a gatekeeper, as the researcher risks exploiting the relationship between the gatekeeper and the person they are introducing (Flewitt 2005). Many researchers believe that children lack the understanding required to provide consent due to their age. However, the focus on an individual capacity to consent implies that some children, who may be considered incapable of giving consent, for example, very young or severely disabled children, cannot be active participants in research (Gallaghera 2008). However, a recent study demonstrated obtaining consent from children with moderate or severe learning difficulties, paying particular attention to avoiding coercion (Lewis 2010).
Similarly, studies in early childhood contexts have demonstrated that even very young children are able to give informed consent if approached ethically (Hedges 2002; Bone 2005; Smitha et al. 2005). Coyne (2010) maintains that studies demonstrating young children's competency abilities support the argument that, irrespective of age, children who can demonstrate understanding of the research and their rights should be allowed to consent or dissent to participation, without their parents' consent being a foregone requirement.

The exact age at which informed assent should be obtained is largely at the discretion of individual researchers and local ethics committees (Green et al. 2003). However, with developmentally appropriate language and information, children as young as five years can understand what research studies are about and are capable of giving voluntary assent (Meaux and Bell 2001).

There is a further distinction in discussions of ethics between consent and assent. Some researchers advocate the use of assent, rather than consent, in gaining children's agreement in certain situations (Balen et al. 2006; Cocks 2006). Assent carries less weight than informed consent, but provides the alternative of an affirmative agreement of a child to participate in the research (Balen et al. 2006b) and a forum through which their willingness to participate can be respected (Mishna et al. 2004). For assent to be valid, “the child must show evidence of understanding the purpose of the research, what he or she is to expect, and what will be expected” (Cocks 2008).

Cocks (2008) explored and developed the use of assent in a project with children with learning impairments, and concluded that it is applicable for research in a variety of contexts. “In reducing reliance on ‘competence’, which in many ways prioritizes language and definable methods of understanding between the researcher and the researched, ‘assent’ increases the accessibility to research for children for whom these measures are difficult to achieve.” (Cocks 2008 p. 263).

Because this research involved both mothers and children, I designed three different information sheets: one for the mothers and two for the children (Children Information A and Children Information B). Children Information A was for the younger and/or less cognitively able children and it consisted of simple printed words, symbols and pictures (Appendix 10 and 12), while Children Information B
could be read by the parents to the older and/or more cognitively able children (Appendix 11 and 13).

The mother information sheets used in this study included the title of the research, the purpose, information about the study, and an explanation of the procedures to be followed. It also gave information on how to contact me and my supervisors, to encourage the participants to ask questions or seek clarification if they had any concerns regarding the study and their participation in it (Appendix 6 and 7). I also designed one consent form for mothers (Appendix 8 and 9), one for children (Appendix 15 and 17), and an assent form for children. Children's consent and assent forms consisted of simple printed words, symbols and pictures (Appendix 14 and 16).

In this study, parents were asked to give consent to their child participating in the study as well as the child themselves. I also checked with the child throughout the interview process that they were willing to continue, by taking notice of their facial expression, vocalisation, eye-pointing, and body movement.

### 7.2.2 Power Relationships

The main key ethical issue that required consideration in the design of the study was that of power relationships, between the children and their parents, the children and myself, and finally mothers and myself. There is an awareness that the adult centredness of most societies and the unequal power relations that exist between children and adults are duplicated in the research process (Morrow and Richards 1996; Harden et al. 2000; Punch 2002). This has led to concerns over how children feel free to refuse to participate in a study, to withdraw during the research or even to give their own views and experiences to adult researchers (McCrum and Bernal 1994). Table 7.1 presents a number of ways that have been proposed for managing the inherent power differentials between child participants and adult researchers (Alderson 1995; Mahon et al. 1996; Morrow and Richards 1996; Thomas and O’Kane 1998; Horner 2000; Ronen et al. 2001).
One of the greatest challenges to overcome during the research was that children tend to see adults as people in power and so may strive to provide the ‘right’ answers or those perceived as desirable (Malcolm et al. 1996; O’Kane 2000). Moreover, parents may be acting as protectors and there is the potential that they may deny children the opportunities for participation or conversely coerce them into participating (Harden et al. 2000). To alleviate this power imbalance, I involved the children in obtaining their consent to participate and by inviting them to choose the location for the interview (Morrow and Richards 1996). I also checked with the child throughout the interview process that they were willing to continue, by taking notice of their facial expression, vocalisation, eye-pointing, and body movement.

- Using methods that allow children to feel part of the research process and which give them the maximum opportunity to provide their views.
- Being responsive to children’s own agendas.
- Involving children as part of the research team.
- Using group interviews.
- Checking on children’s willingness to participate throughout the interview (including being aware of nonverbal cues such as body language).
- Rehearsing with children how to decline participating or answering particular questions.
- In interview studies, giving children control over tape recorders.

Table 7.1 Ways of managing the power differential between children and adults in research (Kirk 2007).

There were also issues of power within the relationships between the children and myself, as they would be unused to being asked for their opinions. To help in ensuring that they did not feel intimidated, they were interviewed with a parent or sister. Therefore, adults who know the child well can help me to communicate with
children and interpret vague responses provided by a child (De Schauwer et al. 2009).

Moreover, cognitive ability is another factor that influences the power dynamics between researchers and children (Mishna et al. 2004), and the power differentials will be more exemplified when the children belong to a marginalised group (Clark 2010). Thus, to lower their power, I used an interview approach, which includes methods that may seem interesting to children and encourage children to communicate in their own ways (Clark 2011). Providing disabled children with an alternate method of communication is empowering because it allows them to participate in research and express their views (Lewis and Lindsay 2000; Graham and Fitzgerald 2011).

Finally, there were issues of power within my relationships with the mothers being interviewed, who might feel a certain obligation to agree to participate in the research, fearing that refusing to take part could affect the services their child would receive. Therefore, I made clear to mothers their right to decline to participate, reassuring them that there would be no negative outcomes if they chose not to participate or to answer any particular questions.

### 7.2.3 Risks and Benefits

Risk assessment had to be applied to mothers and children. There was a possibility of distressing issues being raised or becoming distressed or uncomfortable due to the nature of the questions I had asked. Therefore, I made sure that the mothers and children were fully informed about the content of the interviews and their right to withdraw at any time. The mothers and children were invited to stop the interview and take a break if required. Their right to withdraw was maintained throughout. These small risks were likely to be outweighed by the benefits of participating in the study with the feeling of being pleased that someone was taking an interest in their lives and that they had the opportunity to help make services better for other children with cerebral palsy in the future.

For the children in the study, the risks would seem to have been relatively low, while a potential benefit for them may have been in the opportunity to express their
views on having cerebral palsy. Children are capable at quite a young age of showing a moral sense (Alderson 2008) and they may have enjoyed the idea that their contribution might improve both services and equipment for other children in the future.

7.2.4 Confidentiality

The confidentiality of the research data and its sources were respected throughout the study. All data were generated strictly for this research project. My primary goal was to protect each participant’s identity and to maintain confidentiality throughout the research process. All sources of data, including signed consent forms, demographic information, interview audiotapes, field notes, written transcripts and their translations, and data analysis notes, were stored in a locked cabinet at the researcher's home, while electronic data were stored in password-protected files accessible only to me and my supervisors. Furthermore, the anonymity of the research participants was maintained by substituting anonymous codes for names, with only the researcher and the supervisor having knowledge of the original names of participants. Efforts were made to ensure that participants could not be identified from the quotes used in the results.

7.2.5 Rewards

The National Children’s Bureau in the UK suggests that rewards for children who participate in projects are appropriate (Ward 1997). Each child who participated in the present study received a small thank-you gift after being interviewed. Participants were not told about the possibility of this compensation before the interviews, to avoid any effect on consent and decisions regarding participation. The focus group participants were also offered light refreshments.

7.2.6 Research Ethics and Governance

Ethical approval for the study was gained from the Faculty of Health and Social Science Research Ethics and Governance Committee (FREGC), University of Brighton (Appendix 2) and from the Institutional Review Board (IRB) of the King Fahad Medical City (KFMC), where the study was conducted (Appendix 3).
7.3 Setting

The study was conducted at the King Fahad Medical City, which is located in the centre of Riyadh, the capital city of Saudi Arabia, and is considered to be the largest and most advanced medical complex in the country, with a total capacity of 1095 beds. KFMC comprises the following four hospitals and five centres: the Main Hospital, the Children’s Hospital, the Rehabilitation Hospital, the Women's Specialist Hospital, the Neuroscience Centre, the Diabetic Centre, the Prince Salman Heart Centre, and the Prince Sultan Haematology and Oncology Centre.

The Rehabilitation Hospital, which is accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF), has 154 beds and offers inpatient care, day care, and outpatient services. The hospital receives patients who are referred from other KFMC hospitals and centres, as well as from district hospitals all over the country. Its physiotherapy department provides both inpatient and outpatient services for adults and children. Paediatric physiotherapy services are provided for children under 13 years; according to physical therapy records, more than 30 children with CP are seen daily in the paediatric physiotherapy clinic.

7.4 Launch of the Study

Recruitment for the study was dependent on support from the paediatric in-charge physical therapist. It was therefore important that the paediatric in-charge therapist was informed about the study, felt inclined to be involved, and found potential participants from the paediatric physiotherapy clinic caseload. A meeting was held with the in-charge therapist to explain the purpose of the study and the negotiation of commitment. Details of inclusion and exclusion criteria were explained and the PICT was given copies of the mother’s information sheet, consent form, and recruitment poster. A recruitment poster was posted in the paediatric physiotherapy clinic’s waiting area (Appendix 4 and 5).

At the same time, an email was sent to the chairman of the physiotherapy department to inform him about the study and to show him the IRB approval. Copies
of the proposal, FREGC and IRB approval, information sheet, consent form, and recruitment poster were attached to the email.

7.5 Sampling

While the sample size remains a contested question in the field of qualitative health research, I believe that Sandelowski (1995) provides important directions, suggesting that the sample should be neither too small to support claims of having achieved either informational redundancy or theoretical saturation, nor too large to permit deep, case-oriented analysis.

The first step in an ethnographic study is to define the object of study (Hegelund 2005). The type of sampling associated with this research method is purposive, whereby the researcher chooses a specific group and setting to be studied (Price and Johnson 2006). Purposive sampling is a non-probability sampling method that allows the researcher to target the subjects believed likely to provide a deeper understanding of the topic under study (Curtis and Redmond 2007). For the present study, the sample included mothers who have a child with CP, and the sample was drawn from children with CP who registered at the KFMC for physiotherapy. It was purposive in the sense that all potential subjects were already attending the paediatric physiotherapy clinic.

7.5.1 Inclusion and Exclusion Criteria for the Mothers

- **Inclusion Criteria**
  - Mothers were included if they had children with CP

- **Exclusion Criteria**
  - Mothers were excluded if they had no children with CP.

7.5.2 Inclusion and Exclusion Criteria for the children

- **Children were included if they:**
  - Were aged between 5 and 18 years.
- Had been diagnosed with CP.
- Could communicate either verbally or non-verbally.
- Have cognitive skills to be able to engage with the researcher and be able to participate in the data collection.

Children were excluded if they:
- Were aged less than 5 years.
- Had another coexisting medical condition unrelated to CP (genetic disorder).
- Were cognitively unable to participate in an interview.

7.5.3 The Rationale for the Children’s Inclusion and Exclusion Criteria

Children with cerebral palsy constitute a specific, limited sector of the population of children with disability that cannot be considered to be homogeneous (Begley 2002; Detheridge 2002). It is the significant differences and idiosyncratic features of this population that defines this group as being heterogeneous. One important factor in this study was the children’s level and ability of communication. It is acknowledged that these children may have had impaired expressive and receptive language functioning and they may also have had other cognitive and perceptual difficulties which affected their abilities to respond to stimuli in their environments (Rosenbaum 2003; Stanger and Oresic 2003; Rosenbaum et al. 2007). The children who chose to participate in this study had a range of cognitive capacities and abilities however, all, were able to participate in a reflective discussion of issues related to their perception and experience of the term CP. For some, the depth of articulation and expression was limited and required the use of adjunct talking aids. The decision to include their contribution was made on the strength that this was a novel approach which had not previously been undertaken with this group of children, and that all the children had a voice to be heard.

In order to explore a spectrum of children’s perception and experiences, and capture a diverse perspective, children from a range of ages were chosen. It was also felt that this range would capture the changes that occur through maturity. Moreover,
this age range would also capture the age when autobiographical recall of children develops which is considered to occur between 3 to 6 years of age and becomes very accurate and stable over time (Fivush et al. 1999; Steward 1996; Nelson and Fivush 2004; Fivush and Nelson 2004). This also provides the justification of the lower limit age for the inclusion for the study.

Variation in the stories told by the children was expected because of the heterogeneity associated with cerebral palsy. This variation was welcomed as it provided a broader range of experiences. It was also anticipated and acknowledged that the quality and quantity of data collected would vary in light of this resulting in significant and less significant contributions. However, all children who met the inclusion criteria who volunteered were included in the study in order to give them a voice.

For practical reasons, I decided not to approach severely impaired children or those who had major communication impairments. I did not have the appropriate communication equipment or skills to enable them to express their views, and time was also limited. I also did not include children younger than 5 years because development of an autobiographical memory with which they can comment on prior specific events does not occur until 4 years and older (Nelson and Fivush 2004).

7.6 Recruitment

The participants were recruited through the paediatric physiotherapy clinic at the KFMC Rehabilitation Hospital. Potential child participants were identified by the paediatric in-charge therapist, who gave each mother an information sheet and asked her to consider being part of the study. If they were interested, the mothers were asked if their contact details could be given to me (the researcher).

For mother recruitment, I then contacted each potential participant mother by telephone, stated how I had obtained her contact information, explained to her the purpose of the research study, and told her what would be involved for her. The interested mothers were given an appointment to participate in a focus group at the
One of the challenges at this stage was recruiting mothers. In Saudi Arabia, people don’t like to participate in research, especially when it talks about their family and their experiences because they consider family affairs to be confidential and not for discussion with non-family members. However, I was amazed at the willingness of mothers to participate in this study. Only one mother refused to participate because she did not believe that her child has CP or any type of disability.

For children recruitment, it was decided that the parents would be contacted first to inform them about the project and to seek their guidance about approaching their sons or daughters with regard to participation. This method is similar to that used by Moore et al. (1998) and by Stalker and Connors (2003) when working in a similar situation. The method of recruitment inevitably influenced which children were included in the research, as the parents’ views and values were determining factors in whether each child was contacted (Lewis and Porter 2004). Moreover, some children who would have wanted to participate may have been overruled by their parents and not permitted to do so. It is also important to consider that some young people may have initially agreed to participate only to please their parents (Moore et al. 1998). Obtaining consent directly from each child was thus a vital ethical consideration.

I contacted mothers via a phone, explained how I obtained their contact information, and explained to them the purpose of the research study and the nature of their child’s involvement. Once a mother had agreed in principle for her child to be involved, a meeting was arranged to explain the involvement in detail. Each child was then given the final choice about whether to participate or not. Those children who agreed to participate were given an appointment to attend one-to-one interviews at the physiotherapy department, at a mutually convenient time. I also indicated that the length of time needed for the interview would be between 45 and 60 minutes. This method of contacting and recruiting children was used successfully by Hood et al. (1996) and more recently by Connors and Stalker (2003).
Recruitment of children into this study was much easier than I had anticipated. On reflection, I suspect that this was because children are not commonly invited to give their opinions. There are very few opportunities for disabled children to express their feelings and be given a voice, so this was a novel and exciting opportunity. This was very clear during the interviews, when a 17-year-old girl (Child AN) said:

—Thank you for giving me the chance to talk. It was my wish to talk with someone. Usually when I go to physiotherapy or a doctor’s appointment, my parents stay with me and they answer instead of me. Thank you for giving me this chance. I’ve waited for this for a long time. Thank you, because I never had this chance before.”

7.7 Development and Content of the Focus Group Topic Guide

A topic guide is a list of issues to be explored during focus group sessions. The order of the questions, or the question route, is a sequence of questions in complete sentences (Krueger and Casey 2009). A semi-structured topic guide was developed as the basis for the focus group sessions, to enable me to introduce the topic and then to guide the discussions (Rubin and Babbie 2001). I also developed a pre-planned script of questions to generate a broad yet focused in-depth discussion on the context and various components of the topic (Litosseliti 2003). Four types of questions were used during the course of the focus group sessions: opening question, introductory questions, transition questions, and ending questions (Krueger and Casey 2009). These open-ended questions allowed the mothers to express their opinions and experiences from their own perspectives and in their own words (Patton 2002). The set of questions that I developed was based on the particular area of research and on my clinical experience. The focus group guideline is reproduced in table 7.2.
I. CP Perception
Would you please tell me, in your own words, what does the term CP mean to you? In your opinion, what do you think your child’s diagnosis is?

II. Disclosure
How was the diagnosis presented to you? Do you feel the same about the term now as you did when you first received the diagnosis? After being told about the diagnosis, was any support provided for you? What was the nature of this support? Have you told your child about their diagnosis? If yes, what did you tell him/her? If no, how would you respond to your child if he/she were to ask that question?

III. Experience
Has your life changed since having a child with CP? How did your family role/social life change after the diagnosis? Tell me about a typical day in your child’s life. How do you feel when people describe your child as having cerebral palsy?

IV. Future plans and concerns
How do you see your child when they reach 18 years? How would you prefer your child to be classified?

V. Ending/conclusions and thanks
Would anyone like to add more comments? Or does anyone have anything else that they would like to share with me?

Table 7.2 Mothers’ focus group guideline.

7.8 Setting up the Focus Group Interviews
I enlisted the help of a paediatric physiotherapist with research experience to act as a research assistant and to help conduct the mothers’ focus group. Prior to the session, the research assistant’s role was explained and the issues of confidentiality within this role discussed. I also undertook a practice focus group on mothers who had
normal children, to gain experience and become comfortable with the process (Krueger and Casey 2009). On the day before the actual focus group session, the researcher telephoned the participants to confirm their attendance.

The session took place in the physiotherapy department conference room, in which there was a table, comfortable chairs, and a telephone. The participants sat around the table in a circle to help to ensure an atmosphere of equality and informality and to encourage each participant to engage in the interaction. Name tags for each mother were placed on the table, giving their first names, for example Um Mh (Litosseliti 2003).

I offered food and refreshments for the participants to help put them at ease. Eating food together tends to promote conversation, relax the participants, and aid communication within the group (Krueger and Casey 2009).

7.9 Data Collection Methods

The many different data collection techniques used in ethnography include watching, listening, asking, and examining materials during fieldwork in order to survey the setting (Fetterman 2010). The benefit of using more than one method of data collection is that it improves the validity of the research findings. In particular, using in-depth semi-structured interviews as well as participant observation allows observations to be examined further through exploratory questions (Punch 2002).

I decided to begin with the mothers' focus group, mainly because I wanted to have as much background knowledge as possible when going into the interviews with children. The mothers were encouraged to explore their perceptions of the term CP, their experiences, and their expectations for their children's education, employment and independence.

7.9.1 Mothers’ Focus Group

A focus group interview is a well-established qualitative research method used to investigate participants' perceptions of defined areas of interest (Jowett 1996). It is
a form of group interview that capitalises on communication between research participants in order to generate data.

A focus group was chosen as a method to explore mothers’ knowledge and experiences, because it provides opportunities to ask open-ended questions around the topic and to learn from the issues raised, and was deemed important by the mothers. I was also motivated to use a focus group as I anticipated that mothers would be more likely to give responses which would be accepted and endorsed by their peer groups whilst in their company.

Through discourse and challenges with other group members, the participants assess their own views, thus resulting in the presentation of clear ideas (Krueger and Casey 2009). It allows participants to raise important issues and nuances which researchers often do not foresee. In a focus group, relatively homogeneous groups of participants have the opportunity to stimulate, support and build on each other’s ideas on the topic. They discuss the topic in their own framework and terms. As they become more sensitised to the topic and to each other, participants stimulate each other to take the discussion beyond the rhetorical or habitual. They “open up” and may reveal important material that would not have emerged in direct questioning (Balch and Mertens 1999).

The focus group sessions were semi-structured and audio-recorded to allow mothers to express their perceptions of the term CP in their own words (Sandelowski 2000). Field notes were written by the researcher and the research assistant during and after the interviews, to act as an aide-memoire and to contextualise the discussion.

The focus group discussions were undertaken in Arabic and conducted on two separate occasions with the same participants — mothers of children with CP. Participants answered the questions posed by the researcher, contributed comments, asked questions of other participants, and responded to each other’s questions (Wolcott 1990).

Each focus group session began with an introduction which included a warm welcome from the researcher to the participants. Krueger (1998, p.76) advise that participants should be as comfortable as possible from the first moment of meeting the researcher: “Small talk is essential just prior to beginning the group discussion and moderators must be able to talk casually and comfortably about issues of minor
importance.” After welcoming the participants, I introduced myself and the research assistant, and then gave a brief overview of the study and its purpose, including an explanation of how the findings would be used and indicating that the session would last between 60 and 90 minutes. The researcher must give enough information so that participants feel comfortable with the topic, provide ground rules, and set the tone of discussion (Krueger and Casey 2009). I also explained to mothers that the session would be audio-recorded and transcribed.

To help the mothers focus on the task at hand, I explained to them the format of the focus group, the role of the research assistant, and the nature of their own involvement. The mothers were encouraged to ask me any questions that would help them to decide if they wished to take part and all were given the opportunity to ask questions before and during the research. As explained in section 7.2.1, they were asked to sign a consent form and told that they could choose to withdraw at any point during the interview and that they could refrain from answering any questions if they so wished. In addition, I addressed the issue of group confidentiality by explaining that the subjects would remain anonymous and that all interviews would be numerically coded. It was also made clear that participation was completely voluntary and that the researcher had no affiliation with the service or care which the hospital provided to the child. Finally, I asked each participant if she consented to the group interview.

The initial goal during such a session is to encourage the participants to relax and become involved in the discussion, so at the beginning it is better to ask simple factual questions, rather than complex or controversial ones (Litosseliti 2003). To break the ice, I began by asking each mother to introduce herself, and then proceeded with the discussion by asking open-ended questions as planned. Throughout the sessions, I guided and facilitated the discussion while the research assistant took detailed notes, operated the equipment, and ensured the comfort of the participants (Litosseliti 2003). Once the session was completed, the mothers were thanked for their participation and time.
7.9.2 Follow-up Interview for Mothers

Follow-up interviews were conducted after the preliminary analysis of the data from the two focus group sessions had been completed. The combined use of focus groups and interviews is not unusual and is often recommended when focus groups are being conducted with existing peer groups or when it is thought that the group situation might inhibit individuals from disclosing certain opinions (Michell 1999). Michell (1999) also highlights that because group and individual interviews often elicit different ideas from the same respondents, employing both methods can lead to a more comprehensive understanding of the topic being researched. Therefore, I decided to conduct individual interviews to obtain views from mothers that focus groups miss and to explore certain issues that arise more thoroughly.

Three mothers were interviewed individually to highlight key aspects of their perceptions of CP, to provide an opportunity to share with them and validate my developing interpretation of their experiences, and to explore specific areas that had been highlighted as significant during the focus group discussions. All follow-up interviews, which lasted from 30 to 60 minutes, were audio-recorded and transcribed verbatim. The questions were developed on the basis of the preliminary analysis of the focus group data.

7.9.3 Reflection on the Mothers” Focus Group and Follow-up Interview

As this study was my first experience of doing focus groups, before starting I was apprehensive about generating rich data. I read a great deal of literature on the focus group guideline and sought advice from my supervisors. In the first focus group session, initially, I was slightly tense and worried about being unable to cover the questions. I had some concerns about maintaining a balance between my role as a focus group moderator and observer. However, once I started the focus group session, I found that mothers wanted to share their experiences and seemed to value someone listening to them and being interested in their story. Many commented that they were happy to be part of the research as they felt they wanted to help other mothers with a child with CP. Although, mothers were aware that the research would not benefit their children directly, they were happy to participate because it would help other children in the future. In the second focus group, I saw my role as an active listener and tried to make my presence as unobtrusive as possible by using
minimal verbal interventions. I found that usually I would only need to ask the first question to generate a conversation that shaped itself, often taking in the other concepts I had planned to include. I saw the concepts that appeared spontaneously in the interviews as being as important as those that arose from prompts. To encourage this, I followed Gillham's (2000) suggestion that a research interviewer needs to listen well and say little. Additionally, as my role of participatory observer developed, I became more used to juggling between observer and participant, often moving frequently from one role to another.

I also felt that conducting this research would have had an impact on each participant. It could have had a negative effect on them by bringing up issues that they might not have dealt with completely with regard to the cause of their child's disability. Mothers were guided through the interview process without putting pressure on them to answer when questions might have been painful or distressing. I was aware that sensitive questions might be more difficult to answer in the interviewer's presence and made such questions optional. As it happened, no one took up the option of not answering such questions. However, one of the mothers became quite emotional while talking about her child's disability and her daily life.

One of the challenges I faced throughout the focus group concerned two mothers talking to each other away from our subject and starting to give advice and recommendations to each other. At the beginning I was not sure what to do and how to control this, and then I managed by directing questions to them to overcome the situation.

Generally, using the focus group method, I found out that the mothers were motivated to disclose vital information, especially if the other mothers shared similar conditions and circumstances. However, a possible disadvantage of the group method is that it might be embarrassing for some mothers to disclose sensitive experiences in the presence of others (Krueger and Casey 2009). This was evident in one of the mothers who agreed with the focus group participants that her husband was very supportive; however, when I had an individual follow-up interview with her, she told me the opposite, complained about a lack of help and support from her husband, and had a low level of involvement and responsibility in the family generally.
7.9.4 Interviews with Children

Interviewing is the most common type of data collection method in qualitative research (King and Horrocks 2010) and is inherently flexible and sensitive to multiple forms of expression and individual differences (Willig 2001). Thus, this method is regarded as appropriate for children with disabilities because it gives them space to discuss personal experiences and feelings using their preferred methods of communication (Morris 2003). The key process within qualitative interviews is co-construction of meaning between the interviewer and the participant (Denzin and Lincoln 2011), which means that neither the participants' nor the researchers' views are the focus (Dockett and Perry 2007). The meaning-making process between researchers and children is transformative and fluid (Goodwin and Goodwin 1996; Dockett and Perry 2005) and allows researchers to reflect on their theoretical lens and explore children's perspectives through analysing the meaning of their creative answers (Greene and Hogan 2005).

In qualitative interviews, the interviewer and children can communicate with speech, voice tones, facial expressions, and gestures (Kvale 1996), and children's responses are dependent upon how the researchers ask their questions (Greene and Hogan 2005).

After having interviewed the mothers, I started to organise questions and developed the topic guides for interviewing the children. This topic guide was guided by the predetermined research topics, by my interest and experience as a paediatric physiotherapist, and by what I had learnt from the mothers' focus group. The questions were not fixed and were able to be amended in light of children's responses, giving them voice and allowing them to share their experiences (Kortesluoma et al. 2003; Irwin and Johnson 2005; Kelly 2007). Table 7.3 showed the guideline for the children's interview.

In each interview, I allowed the child to choose a seat before I sat down myself, to ensure the child was comfortable both with the seat which he/she had chosen and with where I sat. Once the child was settled, I introduced myself, gave a brief overview of the study and its purpose, explained how the findings would be used, and indicated that the interview would last about an hour. In practice, the interviews
lasted from 50 to 70 minutes. I asked each child to give his/her consent to participating in the study and I also obtained parental consent for all those under the age of 18. Lewis and Porter (2004) and Moore et al. (1998) state that it is important to respect a young person’s right to agree or disagree to participate regardless of the views of the parents. I told the children that if they became tired and wanted to stop, they should let me know and that we could either take a break or continue the interview at another time. I was also careful to look for clues that they were fatigued or becoming agitated. I informed each child that the interview was being recorded and that they could listen to parts of the recording afterwards if they wished.
I. CP perception
What do you call your problem when you talk about it in your family?
Have you ever heard of the word "CP"?
Do you agree with the diagnosis of CP for you?
Can you describe your understanding of the term CP?

II. Disclosure
Who told you about your disability?
What did they say when they told you that?

III. Experience
Please tell me in your own words how the CP affected your life.
Tell me what it is like for you to live with CP.
Tell me about the experience that you have had with trying to access the school or your classroom.
Tell me about the experience that you have had with trying to access a shopping mall, restaurant, or street.
Tell me about your friends. Do most of your friends have disabilities?
Tell me how you get along with the others.
What makes you feel positive about life?
What makes you different from other kids?
How is your life similar to other children?
Do you think your family members treat you differently?

IV. Future plans and concerns
How long do you think you'll have the disability/CP for?
What do you fear most about your disability/CP?
What kind of treatment do you think you should receive?
Tell me what it's like having to see a doctor or therapist very often.
What is your expectation about your motor level, both now and in the future?
What do you want to be when you grow up?

V. Ending
Do you have anything else that you want to share with me?

Table 7.3 The guideline for children's interview.
When talking about one-to-one interviews, Shucksmith and Hendry (1998) state that the imbalance of power is particularly "acute" when children are being interviewed. To equalise power relations and help children to feel at ease in the individual interviews, I started each interview with some informal conversation on topics such as which school they attended or their favourite food. These were straightforward questions that most of the children answered easily, giving them the confidence to start the discussion and helping them to relax. It was also my aim to build a rapport with them.

I used Talking Mats (picture symbols) with two children who had communication difficulties to facilitate their communication during the interview, to make it more interactive and interesting for them, and to allow them to express their own perceptions. It is suggested that to empower children with disabilities in the research process, researchers should use tools that allow children to communicate (Detheridge 2000). I used two sets of laminated A4 cards — boys’ and girls’ versions — and a mat with the child’s name on to make it more personal, on which participants could stick their chosen statement, building up a picture of how they would describe a typical day, their play activities, and their friends. The cards were colourful, making them more interesting. The area that I want to explore was presented at the top of the card with accompanying symbols. Symbols chosen were as close as possible to the area represented.

Before organising and conducting the interviews, I attended a one-day workshop about Talking Mats to learn how to use them with the children. Their use promoted concentration, interaction, enjoyment, and independence when children were consulted on their preferences, opinions and wishes. The children had the time and space to consider and express their views by placing the pictures on the mat.

7.9.5 Reflection on the Children’’s Interview

To fulfil the aims of this study, I wanted to speak to boys and girls of different ages about their own experiences of having CP and how they went about dealing with CP. I decided that individual interviews would be the most appropriate method to use when asking specifically about children's views. Kortesluoma et al. (2003) suggest that successful interviews are the researcher's interest in the children's
stories and their view of children as being competent interpreters and reporters of their own worlds. However, my previous experience of working with children with CP made this way of working easier to adopt.

Building a rapport is the process of establishing trust between myself and children, which allows the children participants to be comfortable in opening up to me (Holstein and Gubrium 2003; King and Horrocks 2010). In most of the interviews, rapport building was successful, and the children demonstrated trust towards the interviewers through both verbal and nonverbal means. For the youngest child, the presence of a rapport was signified by sitting close to me and allowing me to play a puzzle with him. Another child a 17-year-old girl, said to me that she preferred to talk with me alone, without the presence of her mother.

As Whitehurst (2007) noted, I found that some of the children with more severe CP had limited attention and could easily be distracted by noises or events happening outside the room. For these children, I followed Irwin and Johnson's (2005) suggestion, which is to be cognisant of children’s language and cognitive abilities and structure their questions accordingly to keep the format of the questions. Therefore, I kept the questions short and concise and I was flexible with the wording or setting of the question. Morris (2003) points out the need to separate the child's needs from disabling barriers such as the attitudes of gatekeepers or lack of access to materials. I draw on the advice of Watson and his colleagues (2000) who maintain that “research techniques cannot be applied universally to all children and therefore should be questioned reflexively during the research process” (p. 203). Adaptations to the questions were made on an individual basis with the emphasis on overcoming barriers to the participation of each child in the study and ensuring that all of the children were supported to participate and to communicate their responses in the most suitable way according to their abilities.

Interviewing children also raised many challenges. One of the challenges was for me to become familiar with the children and to understand their communication style. Using Talking Mats with two children to explore their meaning and understanding of the learning process showed me the advantage of using the Talking Mats to facilitate the interview process. I adopted the ideas of the ‘Talking Mats’ (Murphy
1998), a visual framework using symbols to help two children with communication difficulties to communicate, as a basis from which the research tool was developed. To access children’s views about their experience and perception, the first step was to identify the areas that I would like to explore. Based on the communication with parents before the children’s interview, I identified three areas to explore including describing a typical day, their play activities, and their friends.

It also assisted in reducing power of myself as a researcher and increasing power of the children in the study. The data obtained would only be useful if we could ensure that the children understood the questions and their answers were likely to be reliable (Rabiee et al. 2005).

The interview for these two children took 70 minutes, because I spent approximately 15 minutes with each child prior to the interview to understand their way of communication better. It is worth mentioning here that using Talking Mats with Saudi children and involving children in research was a new experience for me and for the children; however, children found it entertaining and fun. Indeed, I felt this was not just a new experience for children. Parents were pleasantly surprised to see the child getting so much involved. A father of an 8-year-old girl told me that he never thought his daughter could concentrate for so long.

Despite all of our efforts to ease communication, there were times in which I encountered difficulties, for example children refusing to respond because they wanted to play or they just felt tired. This was largely overcome by staying a long time with the child and giving them frequent breaks. In many cases, communication with a parent prior to the interview helped to overcome these problems. However, it was important to learn from every interview and take this learning into account when planning subsequent interviews.

7.9.6 Participant Observation

Ethnography is learning about people’s lives from their own perspectives and their own experience. It involves not only talking to them and asking questions, but also observing them, participating in their lives, and collecting information which relates
to their situation (O’Reilly 2005). There are two types of observation used in ethnographic research: participant and nonparticipant (Roberts 2009). —Participant observation involves not only gaining access to and immersing oneself in new social worlds, but also producing written accounts and descriptions that bring versions of these worlds to others.” (Emerson et al. 2001, p. 352) Ethnographic researchers immerse themselves in the culture under study to experience events in the same way as the people of that culture. This immersion gives them a deeper understanding of the people they are learning from, through seeing things from their perspectives (Liamputtong and Ezzy 2005; Fetterman 2010).

Participant observation helped me to understand things that might not have been revealed through interview data alone; it also helped me to make sense of observed events and to identify patterns of behaviour (Boyle 1994; Roper and Shapira 2000). I considered it appropriate to collect data by this means because the main objective of the qualitative phase was to explore and understand participants’ perceptions of CP. Observing mothers’ nonverbal cues and their behaviour and listening to talk between mothers during the group interviews proved to be crucial resources for generating data. Accepting that there will be some kind of influence from the researcher on the data and trying to understand this in context are part of the reactivity of research (Holloway and Wheeler 2010).

During the focus group sessions, the observation of some mothers was straightforward in that nonverbal cues and body language were noted. However, there were three mothers who chose not to expose their faces because of their religious beliefs, which made the interpretation of their body language more difficult. Initially, I assured them that the room was closed and that no male would be allowed to enter, hoping to make them comfortable enough to uncover their faces, but they preferred to stay covered, which made it very difficult to capture their facial expressions. They even remained covered while drinking and eating. One mother did uncover her face, but she broke down and cried when I asked her about a typical day in her life, and then replaced her veil to hide her emotions. For a moment, the other mothers, the research assistant and I all fell quiet, and then we continued with the focus group session.
I also noticed that one of the participants was dominant and talked a lot, giving advice and instructions to other mothers regarding traditional treatments and those specified in the holy Quran. In the second focus group session, the mothers were more comfortable than in the first one, greeting each other and chatting together while waiting to start the session.

7.9.7 Field Notes

Field notes helped to capture practice and dialogue which, in turn, created my own understanding and, at times, produced new meaning. Grove and Burns (2005) stress that qualitative researchers must be flexible not only in their research design, but also in how they view the world, ready to change their perspectives as new aspects of the world are unveiled. The researcher needs to be open to new ideas, because critical research has an emancipatory intent, not only for the researched but also for the researcher (Street 1992; Carspecken 1996).

Ethnographers collect many different types of data; field notes are an important source of such data (Fetterman 2010). An ethnographer's goal is to translate the deep, hidden meanings of a participant’s actions in the observed culture to the reader by using detailed descriptions (Geertz 1994).

During the group interviews, the research assistant took notes, describing the participants, their reactions and feelings about the focus group, and attempting to capture the exact phrases and statements, nonverbal cues and behaviour such as gestures and posture. These notes complemented the spoken word by contextualising the sessions. They also provided a fallback position in case of any unexpected problems with the digital recorder (Krueger and Casey 2009).

Immediately after each session, the researcher went through the notes with the research assistant to make sure that all comments were legible and clear. I also wrote down my own observations of the sessions (Patton 2002; Litosseliti 2003), including what I felt was striking, surprising, paradoxical or eloquently articulated. I recorded demographic information such as each participant's age, marital status, number of family members, education level, and the child's age and diagnosis (type of CP). These data were provided by the participants themselves at the end of the session.
7.10 Data Management

Before and immediately after each interview, I checked the equipment to ensure proper functioning. All data were generated strictly for this research project.

7.11 Transcription

Immediately after the interviews, field notes and audio-recorded interviews were transcribed in Arabic. The transcribed focus group data were checked with the audio recordings to ensure accuracy. The interview notes were reviewed and elaborated as needed.

The transcription process involved listening to the interview tapes several times, during which notes were taken about the tone of voice used by the children and mothers, pauses in conversation, and emphasis on certain points which were important to the mothers or children for future reference during the process of analysis.

Transcribing the interviews and focus group by myself allowed me to become more involved in the research process by being able to reflect on the actual transcript content as well as the actual interview itself (Wellard and McKenna 2001; Davidson 2009).

7.12 Translation

The focus group topic guide, consent forms, participant information, and recruitment poster were originally written in English and, thus, had to be translated to Arabic. To ensure that the Arabic version was close to the English version, a back-translation technique was used. To test the translation equivalence, the original forms were first translated from English to Arabic by a bilingual translator and then back-translated from Arabic to English by a bilingual translator. The two versions of each form were then compared to confirm translation equivalence. This was done by employing professional translators in Saudi Arabia to ensure quality and accuracy. However, the forms were adequately translated to Arabic without losing any meaning.
Moreover, the focus groups and the interviews were conducted and transcribed in Arabic, and subsequently translated into English. I followed the same method of translation consent, information and assent form, and recruitment poster. Working in two languages is not an easy task, as I experienced. Some of the challenges encountered during the translation process of the interviews and focus group were the absence of equivalent words in the English language, and the presence of words which had more than one equivalent word. (Consequently, a discussion with the translator ensued to verify that the words which best fitted the context of the questionnaire were chosen.) The main challenge was to overcome the major differences between the Arabic and English languages. The Arabic language uses a style which is long-winded (as opposed to English, which is much more succinct), does not rely on vowels, and uses a structure which does not resemble the English language in any way. The use of professional translators, however, helped to overcome these challenges.

7.13 Approach to Data Analysis

In qualitative research, data analysis is a complex, analytic and creative process in which some form of classification or coding is inevitably involved. It is an active process in which researchers identify salient patterns or themes by reading through data iteratively and then attempt to explain themselves by looking for connections among the patterns and the context (Lincoln and Guba 1985).

Data analysis is also one of the most difficult aspects of qualitative research as a result of the nature of the research process, which “invariably hides a trail of difficult and questionable decisions” (Grant-Davie 1992, p.270 in Brice 2005, p.159). Hammersley and Atkinson (2007, p158) advise that analysis is not a distinct stage; it is rather an activity which links into all stages of the ethnographic process. It is a necessarily iterative process: “there should be movement back and forth between ideas and data.” For this study, I followed Carspecken's (1996) five stages of analysis, not in a rigid sequence, but in a recursive or cyclical way.
7.14 Carspecken’s Five Stages of Analysis

Carspecken's (1996) five-stage analytical process is extremely intricate. It involves adding meaning by naming all possible connotations, including "meanings that might be read from the timing, tone, gestures, and postures of each act". In essence, it involves the following:

Preliminary steps: Creating a list of research questions and a list of specific items for study, and examining the researcher’s value orientations, before the researcher enters the research site.

Stage 1: Compiling the primary record through the collection of data.

Stage 2: Doing preliminary reconstructive analysis.

Stage 3: Generating dialogical data.

Stage 4: Discovering systemic relations.

Stage 5: Using systemic relationships to explain the findings.

Stages 1 to 3 can represent any ethnographic research design, while 4 and 5 specifically engage the elements of critical theory.

The first three stages of Carspecken's framework use critical analytical models to reconstruct cultural structures and themes, whereas the last two stages are designed to discover routine social actions and reproduce the systemic relations that coordinate activities across various reaches of space and time (Georgiou and Carspecken 2002).

Below is a detailed description of how Carspecken's five-stage approach was employed in this study.

**Preliminary Steps: Creating a list of research questions and a list of specific items for study, and examining the researcher’s value orientation**

The first step was to create a list of questions relating to mothers' and children's perceptions of the term CP, based on a review of the literature and on my own experiences as a paediatric physiotherapist working with mothers of children with CP.
This was followed by the drawing-up of a specific list of the information needed to address these questions. The final step was the exploration of the researcher's value orientations to put a check on biases. I went through these questions with my supervisors and sought their feedback. This process was intended to raise my awareness of biases so that I could check for them while compiling field notes and formulating research questions. The discovery of biases is a process that continues throughout a research project and enables readers, to some extent, “to see behind” the values that may govern the analysis (Carspecken 1996, p. 41). Bias checks include methods such as writing field notes during and after the interviews and member checks.

<table>
<thead>
<tr>
<th>Potential interest to be investigated</th>
<th>Information needed to address this issue</th>
</tr>
</thead>
<tbody>
<tr>
<td>How children with cerebral palsy and their mothers perceive the term CP</td>
<td>Personal beliefs</td>
</tr>
<tr>
<td></td>
<td>Understanding of the term CP</td>
</tr>
<tr>
<td></td>
<td>Cultural and religious influences</td>
</tr>
<tr>
<td>Mothers' experiences on learning their child's diagnosis</td>
<td>Acceptance</td>
</tr>
<tr>
<td></td>
<td>Reactions</td>
</tr>
<tr>
<td>Did healthcare professionals involve children/mothers in the healthcare plan?</td>
<td>Communication</td>
</tr>
<tr>
<td></td>
<td>Power relationships</td>
</tr>
<tr>
<td>How do mothers of children with CP describe their acceptance?</td>
<td>Cultural and religious influences</td>
</tr>
<tr>
<td>What are the children's/mothers' lived experiences of CP?</td>
<td>Cultural influences</td>
</tr>
<tr>
<td></td>
<td>Support</td>
</tr>
<tr>
<td>What is the public attitude towards children with disabilities?</td>
<td>Discrimination</td>
</tr>
<tr>
<td></td>
<td>Bullying</td>
</tr>
<tr>
<td>How does a child with CP get along with others?</td>
<td>Relationships</td>
</tr>
<tr>
<td></td>
<td>Communication</td>
</tr>
<tr>
<td>What are the problems and issues facing disabled children?</td>
<td>Inclusion</td>
</tr>
<tr>
<td></td>
<td>Accessibility</td>
</tr>
<tr>
<td>What was the impact of the child’s disability on the family?</td>
<td>Social exclusion</td>
</tr>
<tr>
<td>How are gender and severity of disability associated with inclusion?</td>
<td>Factors affecting inclusion</td>
</tr>
</tbody>
</table>

Table 7.4 Preliminary research plan.
Stage 1: Compiling the primary record through the collection of data

Prior to the main data collection, a primary record was developed. The primary methods of data collection involved the Saudi mothers’ advisory group (Appendix 1) and field notes. Carspecken (1996) explained a primary record built up through note-taking, audio recordings and, if desired, video-taping. The mother’s advisory group was intended to refine the research question as well as to determine to some extent my own value orientations. It also enabled me to develop and structure the guidelines for the mothers’ focus group and for the children’s interviews. Throughout this stage, I tried to maintain supportive, non-authoritarian relationships with mothers, to actively encourage them to question my perceptions and to ensure their confidentiality (Carspecken 1996).

Stage 2: Preliminary reconstructive analysis

Carspecken (1996, p.93) refers to the second stage as reconstructive analysis because it reconstructs into “explicit discourse, cultural and subjective factors that are largely tacit in nature”. During this stage of the study, I began to speculate as to the meanings of the observations and to identify key issues that required exploration. The analysis was preliminary, being checked, expanded and changed during stage 3, when data were collected from the mothers’ focus groups, follow-up interviews and interviews with the children. The preliminary reconstructive analysis involved an interplay between low-level coding, initial meaning reconstruction, and high-level coding.

During this stage, I spent many hours reading and rereading the transcripts, noting initial meanings and impressions in the left margin. Following further reading of the transcripts, I highlighted possible interpretations, and then identified the general categories or themes and classified each piece of data accordingly. Thus, based on the low-level coding, whose aim was to describe actions, behaviours and events (Table 7.5), I began higher-level coding by making inferences about the meaning of actions or events. As Carspecken (1996) noted, coding can be low-level or high-level. Low-level codes are usually objective in nature, in that the activities commented upon are open to multiple access, although some abstractions or inferences may be incorporated into low-level coding. Carspecken (1996) argued
that high-level codes are dependent upon greater amounts of abstraction and are required to be able to generalise findings that have emerged from various forms of qualitative data analysis. High-level codes assist with determining analytic emphases to be employed in the discussion of findings, though Carspecken (1996) warned that such codes should be backed up with exemplary evidence of analysis.

Over time, as more information was collected and organised, I repeated the analytical procedures employed at this stage.

<table>
<thead>
<tr>
<th>Excerpts from primary record</th>
<th>Low-level coding</th>
<th>High-level coding</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Cerebral palsy means paralysis of the brain. My child has normal IQ. He is moving his four limbs.”</td>
<td>Cerebral palsy is a condition of the brain</td>
<td>Reject the term of CP</td>
</tr>
<tr>
<td>“My child is normal. He has only delayed in growth and development. Now he has started to stand, walk, and descending and ascending stairs.”</td>
<td>Justify why they believe her child is normal</td>
<td>Denial of CP</td>
</tr>
<tr>
<td>“All the people say, ‘oho he is not walking’, and they look at him and his wheelchair like a person that comes from another planet. They say, ‘he is handicapped; why he is like this?’”</td>
<td>Saudis have negative attitudes towards disability</td>
<td>Stigmatisation</td>
</tr>
</tbody>
</table>

Table 7.5 Stage two: Examples of a coded reconstruction of a primary record.

**Stage 3: Generating dialogical data**

The third stage serves to give participants a voice in the research process and a chance to challenge material produced by the researcher” (Carspecken 1996, p. 155). To give the mothers and children a voice, I held focus group sessions and follow-up interviews with mothers and individual semi-structured interviews with children. During this stage, I adopted the joint roles of facilitator and participant observer. I
maintained a supportive and safe environment with participants by stating the intent of the interviews.

In stage three, common themes in the data are sought (Table 7.6), as generated from the responses of all interview participants who have been asked similar questions. Inferences are recorded alongside pertinent verbatim excerpts, to be later crosschecked with other sources of data.

<table>
<thead>
<tr>
<th>Excerpts from verbatim transcript</th>
<th>Theme identified</th>
</tr>
</thead>
<tbody>
<tr>
<td>M6: “My son has delayed motor development. I know that my child is improving by the time; now he has started to talk and express himself and he has started to walk, too.”</td>
<td>Rejection of the term CP</td>
</tr>
<tr>
<td>M6: “I believe what happened to my son was a strong Eayn (evil eye) that hit his health. I felt it one day when I had a large gathering in my house and one of the ladies, without saying Masha’Allah (God protect you from envy), said, <em>you have a pretty child</em>.”</td>
<td>Evil eye and jinn causes of CP</td>
</tr>
<tr>
<td>M6: “In our society it is very shameful to have a handicapped child. If you have a handicapped child, then it is shameful to take him out with you — you have to hide him. Society blames the mother.”</td>
<td>Blaming mothers</td>
</tr>
</tbody>
</table>

Table 7.6 Stage three: Example of theme identification from mothers’ focus group.

**Stages 4: Discovering systemic relations**

In stage four, according to Carspecken (1996), the idea is to discover particular systems’ relations by analysing several related sites. In this study, systems’ relations are examined across two main sites within children and mothers. In this stage, the reconstructive analysis conducted throughout stages 1 to 3 was interpreted to identify systemic relations. The new themes identified and existing themes revisited at this stage led to the development of systemic relations or clusters of data which could be quantified, compared and contrasted with other emergent patterns (Carspecken 1996). This assists with the validation of the inferences and truth claims made by the researcher (Miles and Huberman 1994).
According to Carspecken (1996) the validity requirements for stage four include the appropriate reconstruction of cultural forms evident in several sites, followed by a comparison across sites. Special interviews and group discussions should also be conducted for a stage four analysis.
Excerpts from focus group transcript

M1: “My son doesn’t ask about the condition or disease but he always says, ‘if the God is willing, I will be able to walk’. When he was younger, he never asked me. Now he asks me, ‘why am I not like my brother and sister? Why am I not walking?’ I answer him, ‘son, pray to the God to help you! If the God is willing, you will be able to walk and you will be like your brother and sister’. I am praying to my child to be able to walk and waiting for the God to accept my prayer.”

M1 believes that God predetermines disease and cure. She utilised religious beliefs to maintain her child’s hope, as well as a treatment tool to cure her child from disability. This belief emanated from a core Muslim faith, namely that all that went on in life was mandated by divine will.

M1: “Cerebral palsy means paralysis of the brain, which means that in the brain, the child will be affected depending on the point of cerebral palsy. Some children will have problems with hearing, vision and intellect. Others will have difficulty in movement and mobility.”

M1: “I am not convinced that my child has cerebral palsy. I believe cerebral palsy affects the brain. The child may have brain atrophy. In my point of view, cerebral palsy has several types. I am not convinced that my child has cerebral palsy; I am not convinced at all. I know my child. He is improving by the time; now he is 13 years and half and he has started to stand and walk. His brain is normal. Cerebral palsy affects the brain.”

M1 is aware that cerebral palsy is a condition of the brain and that it may result in altered movement. However, she keeps repeating that her child does not have CP, and she also views her child with a disability as a normal child. The mother tried to focus on the child progress because normalcy may give her hope that her child could still be healthy and normal. Also, she rejected the term of CP to avoid community stigmatisation.

M4: “People in Saudi Arabia see the cerebral palsy child different than others. They treat her as aliens, especially when she gets out in the shopping mall or at the school. I don’t like Saudis’ attitude toward the handicapped. We went to Jordan and to Kuwait, but I did not see this attitude. It is only in Saudi Arabia. The women in our society blame the mother if she has got a child with cerebral palsy. On my second birth, all the women were waiting to see if I got a normal or handicapped child.”

M4 talked about the negative attitude and stigmatisation from the Saudi community, school and society towards her daughter. This suggested that the people of Saudi society do not have accurate information or an understanding about disability or children with disabilities. This might be due to children with disabilities being invisible to the public. M4 also felt blame from other women in the society for having a child with CP. This might be due to the women in society believing that CP is a hereditary disease and the mother having caused the child’s disability.

Table 7.7 Stage four: Example of analysis and interpretation from mothers’ focus group transcript.
Stage 5: Conducting systemic analysis

Stage five goes beyond stage four by discussing findings in terms of existing theory. During stage five, the researcher attempts to ‘fit’ or connect the highly specific causal relationships built up over stages one through four and an existing social theory. But matching alone is not quite enough to produce a convincing argument. As indicated above, you must build abstractions of your empirical data to the point where a fit can be recognised (Carspecken 1996). Therefore, I looked at the causal relationships between the mothers’ and children’s perceptions of CP, the children’s experiences, and participants’ cultural backgrounds. I also tried to suggest reasons for these experiences and cultural forms that had been reconstructed.

Carspecken (1996) argued that the basic strategy in stage five is to discover how the research participants meet their material and social-psychological needs to characterise their interests. Why they must meet their needs in these particular ways can be investigated by examining their access to cultural, political and economic resources (Carspecken 1996). Therefore, mothers and children play a role in the analysis during stages four and five.

7.15 Summary

In this chapter I have sought to describe my methods of data collection, the decisions that I made during this process, and the challenges that I encountered. In summary, the site of the study was the physiotherapy clinic at KFMC in Riyadh, the subjects were children with CP and their mothers, and the processes of data collection and analysis were informed and guided by Carspecken’s five-stage model. The next chapter presents the findings of mothers’ focus groups and interviews.
Chapter 8: Mothers’ Focus Group and Interview

Findings

8.1 Introduction

This chapter focuses on the findings from two focus groups of six Saudi mothers and follow-up interviews with three mothers. It explores several aspects of disabled children's lives from their mothers' perspective, their role and relationship with the family and community, their experience and their own concerns about having a disabled child.

The chapter is presented in two sections: the first presents the detailed description of the participants of the study and the second the common themes elicited from the mothers’ focus group. In this section, concerning illustrative quotations taken directly from interview transcripts, the emphasis is on letting the participants speak for themselves. The “thick description” (Denzin 2001) provided an avenue to present a broad range of experiences. This form of description also provides the reader with an opportunity to enter into this study and better understand the reality of the participants.

8.2 Mothers’ Demographic Characteristics

The six mothers participating in this study all originated from Saudi Arabia. The ages of their children ranged from 4 to 14 years. Two of the mothers were widowed, and four were married to the biological father of their children. All the mothers were housewives, with large families of more than five members. Five mothers had maids who helped with taking care of the children as well as household chores. One mother had twins of whom one was diagnosed with CP, another also had a child with CP and one with Down's Syndrome. One mother was illiterate and never attended school, two had intermediate education, two graduated from high school,
and one had bachelor’s degree. All mothers were from middle-class socioeconomic background. Specific demographic information is shown in Table 8.1.

<table>
<thead>
<tr>
<th>Mother</th>
<th>Marital Status</th>
<th>Education Level</th>
<th>Occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>M1</td>
<td>Single mother (widowed)</td>
<td>High school</td>
<td>Housewife</td>
</tr>
<tr>
<td>M2</td>
<td>Single mother (widowed)</td>
<td>Illiterate</td>
<td>Housewife</td>
</tr>
<tr>
<td>M3</td>
<td>Married</td>
<td>Intermediate</td>
<td>Housewife</td>
</tr>
<tr>
<td>M4</td>
<td>Married</td>
<td>Intermediate</td>
<td>Housewife</td>
</tr>
<tr>
<td>M5</td>
<td>Married</td>
<td>University</td>
<td>Housewife</td>
</tr>
<tr>
<td>M6</td>
<td>Married</td>
<td>High school</td>
<td>Housewife</td>
</tr>
</tbody>
</table>

Table 8.1 Summary of Mothers Characteristics

**8.3 Mothers’ Themes**

The focus of this critical ethnographic study is on disability, children and mothers’ voices in Saudi. Bronfenbrenner’s ecological theory was used as a base for this study to help with the understanding of mothers’ perceptions. This theory describes the mothers’ experience in various subsystems.

Mothers’ themes were identified through prolonged reading and exposure to the focus group and follow-up interviews. The identification of the themes was influenced by the research question, the ecology theory and my own interpretation of the data. Although the analysis was based on my own interpretation of the data, this did not negate my critical realist approach, and shaped the way to adopt a system suitable to analyse both the macro structural elements and the micro individual aspects.
Initially, several themes were identified. However, after careful consideration of the context of the focus group discussions and my notes, three different themes emerged. These were:

Theme 1: Religious and cultural beliefs
Theme 2: Mothers experience of having a child with CP
Theme 3: Community Attitude and Support

These essential themes had several subthemes that further express the thematic elements of each theme and offer an opportunity to examine this phenomenon in new light (Figure 8.1). It is recognised that there is an overlap among the themes. Each theme and its subthemes are discussed separately bringing in rich descriptions from the patients' interview quotes.

![Diagram showing the three main themes and subthemes, which emerged from the analysis.](image)

Figure 8.1: Diagram showing the three main themes and subthemes, which emerged from the analysis.
**Theme 1: Religious and Cultural Beliefs**

Religious beliefs and cultural norms were found to be major factors in the mothers’ perception of their children’s disability. As discussed earlier in Chapter 2, the natives of Saudi accept that all aspects of their life, whether good or bad, happy or tragic, as tests from the God, and how they respond to these tests reflects their faith and eventually their place in the life hereafter.

In the religious and cultural belief theme, three sub-themes were identified including Evil eye and Jinn cause CP, accepting the fate, praying to God —Allah” to cure their child’s disability and aspiration and optimising the child’s future.

**Subtheme 1: Evil eye and Jinn Cause CP**

Mothers spoke of their understanding of the causes for having a child with disability. Most strikingly, all mothers made references to theologically based explanations to having a child with disability. Some of the mothers considered the role of the Evil Spirit and devil (Jinn), as the causation of the disability of their children. Although medical specialists diagnosed their child’s condition, they still harbour the belief that their child’s disability resulted from someone casting an 'evil eye' on them. In Saudi culture, certain beliefs are held which are considered to have a cultural and religious basis. One such belief which was prevalent in the narratives was the shared belief in the evil eye, where an envious person might comment or compliment someone without saying —Masha'Allah”, (God protect you from envy).

One mother of 6-year-old boy said she based her belief on specific incidents including when a woman commented or complimented her son without saying —Masha'Allah”. She loosely blamed the 'evil eye' for her child’s disability. She said:

> I believe what happened to my son was a strong ayn (evil eye) that hit his health. I felt it one day when I had a large gathering in my house and one of the ladies without saying Masha'Allah (God protect you from envy), said, _you have a pretty child_.” M6
Such beliefs about the cause of disability hinder the process of treatment. In this case, the mother became uncooperative and refused to follow certain medical advice. However she continued with rehabilitation services and traditional treatment.

―Deep in my heart I feel it is Jinni that caused my child’s disability. I went for traditional treatment and they advised me to remove the pump, but his doctor refused to take it out and I asked him to stop the medication under my responsibility.” M1

Such beliefs also encourage mothers to seek assistance outside of the medical and rehabilitation services. Some mothers reported that traditional healers had advised them that the disability was due to Jinn. The use of a traditional healer is a cultural norm and provides another treatment option. Some mothers sought solace in this belief as an alternative to exploit all possibilities of treatment hoping to find a cure for their child. Healing through the Qur’an has been well known in Muslim culture, Verses of the Qur’an are used by Muslims to protect children from the harmful effects of the ―evil eye” and ―Jinni” that causes disability. Their belief and trust in traditional healing made them state significant improvements in their child’s functional status.

―I have found that reading the holy Quran was the best treatment. My child was very involved; he was not able to sit. Today he can sit and stand. Today he got out of his bed.” M6

Subtheme 2: Accepting Fate

All mothers perceived that their child’s disability was the will of God, and they believed that having a disabled child was ―fate” or ―divine intervention” and that God (Allah) chose them to care for a child with CP. This belief emanated from a core Muslim faith, namely, that all that went on in life was mandated by the divine will. Mothers believe that having a child with CP was written by God and it could happen to anyone. Equally they believed, and appreciated, that health is the greatest blessing from God. This appreciation of health is supported by accepting that whatever God decrees will take place and if he does not, will not take place. In
Islam, it is vital to accept Allah’s power, knowledge and control of destiny, and willingness to submit to what He has prescribed for us.

— Anyone of us might have a car accident and become handicapped. This is from God, and it is out of my hand to have a child who is not walking.” M1

Consequently, religious beliefs play an important role in ways of managing and dealing with challenging circumstances of their child’s disability. In addition, religious belief helps mothers cope with the disability, making them more resilient and calmer in the face of setbacks. One of the mothers with a severely disabled child believed that God had given her the support and strength to be able to cope successfully with her child and his disability.

— God gave me strength and faith, which helped me handle my child’s disability and for also handling the other child with Down syndrome.” M5

All the mothers, regardless of the severity of their child's disability, shared similar approach to religion. They were thankful for their religion, and recognised the importance of holding on tightly to Islamic principles which involved suffering, patience and reward. The repeated use of the expression "Thank God!" by mothers during the focus group interviews which they really mean confirms their faith in the actions of God. Mothers expressed their gratitude to God for several things such as improvement in the motor ability of their children. The belief in God is also linked to the mother’s reliance on God to cure their children. This will be discussed in the next subtheme.

**Subtheme 3: Praying to God “Allah” to Cure their Child’s Disability**

All mothers expressed a deep trust in God, and relied on him for their child's cure and long-term health outcome. They believe that God predetermines disease and the cure too, and that they should try to prevent disease by praying to God. In Islam, one can pray at any time, at any place and under whatever circumstances. Throughout the interviews, prayer was constantly invoked by mothers as they related their
experiences and responded to questions. Prayer can be considered a tool used by all
the mothers, regardless of their child’s severity. They also reported that they always
utilised religious beliefs to maintain her child’s hope. The mother with a severely
disabled quadriplegic child used prayer for inner strength to help her cope with her
child’s disability.

The mothers gained spiritual strength from practicing religious beliefs, and also got
inspiration to maintain positive attitude about their children’s improvement and
progress and care-giving responsibilities.

“I am praying to my child to be able to walk and waiting the God to
accept my prayer. I always say, Son pray to the god to help you! If
the God wills you will be able to walk and you will be like your
brother and sister.” M1

Subtheme 4: Aspiration and Optimising the Child”s Future

Mothers are convinced that their child will be cured of the condition because of their
fatalistic belief (God’s will). The mothers hoped for improvement in their children's
impairments that would enable them to have a future, and that they might be able to
lead a normal life like other children. The mothers compared their children's abilities
to those of their able-bodied peers, and hoped that their children would be able to
walk in the future. This aspiration was expressed by the mother of the young
children who hoped to have more advanced and improved medical treatments over
time, which might improve their children's abilities.

Mothers hoped that their children would be able to walk, take care of themselves,
and have an occupation. Mothers also expressed their interest in including their
children in as many “normal” activities as possible and to integrate them in the
society and community.

A mother of a 13-year-old boy expressed her concern through hoping for acceptance
by society. She wished to see her disabled children improve, have greater
independence and greater social inclusion in future.
I want Ab to be independent and able to live like other normal children. I want the society to accept him and I wish that people would stop giving him strange and petty looks.” M1

In Saudi culture, disabled people lose out in marriages and the fate of disabled women even worse than that of men. This is linked to the widely held view that disability reduces their ability to meet their gender roles in marriages. Women are seen as less able to provide the practical care for children and men viewed as less likely to be able to provide the financial security for the family. Saudi families are unwilling to consider marriage proposals to someone with disability as it is not socially acceptable. This is because of practical difficulties and also because of the fear of passing on a genetic defect to children. This became apparent when a mother said that she hoped to find a wife for her son, because she believed that there are many obstacles to marriage for people with disabilities, and such marriages were perceived as shameful and burdensome for families and wives.

"I see him getting married. From now I am looking for the right girl. When I see a pretty girl I say, ‘she will be my son’s wife’. I always ask myself how I will find the right girl for him. One of my relatives has a spinal cord injury and he is a good-looking man. He has a job but has difficulty getting married. He did not find a girl to accept him as a husband, because he is disabled.” M6

The severely disabled children, especially girls, were seen as frail and they would need somebody to look after them even in adulthood. According to Saudi culture, the girls, were seen as vulnerable and difficult to live alone. This perception did not apply to only disabled girls, but of course to all girls in general. The mothers dreaded the future, particularly in relation to dealing with puberty issues. The mother of a 14-year-old girl shared her anxiety and feelings of worry about the future of her daughter.

"It is very difficult. I don’t want to think of the future. It is difficult. A lot of issues such as menstrual cycle (period). I don’t know how she will deal with it. No, I don’t want to think.” M4
Concerning employment, the mothers felt that their children could get employment and become occupied. The mothers hoped that the services needed by their disabled children would improve, and voiced concerns about the shortage of rehabilitation service. The mother of a 13-year-old boy was disappointed and sad with the lack of progress in her child’s functional abilities. She hoped that she would get a chance to go abroad for better and advanced therapies. She believed there is hope if she did not give up on any therapy.

“Lately AB did not show progress in his walking ability, but I keep hoping that he will improve one day. I wish I could take him abroad for intensive physiotherapy treatment on daily basis, 2-3 hours per day, it would be helpful.” M1

Theme 2: Mothers’ Experience of having a Child with CP

This theme focuses on the meaning of the term CP, as narrated by the mothers according to their understanding and expectations, their view about their children’s disability and how it affects their role as a mother as well as the family. The mothers were in a way upset with the changes that happened in their lives and because of concern for the welfare of their disabled children. Five subthemes emerged from this theme including: mother’s perception of the term CP, rejection of the term CP, diagnosis and its consequences, feeling about having a child with CP and mother’s extra caring responsibilities

Subtheme 1: Mother’s Perception of the Term CP

This theme focuses on the meaning of the term CP, as narrated by the mothers as per their understanding. The perception of the mothers begins with the question, what does the term cerebral palsy mean to you? While all mothers referred to theological explanation for the cause of their children disability, they also gave medical explanations such as “brain atrophy” and “lack of oxygen”. In general, mothers agreed that CP is a condition of the brain that resulted in altered movement. The mother of the 13-year-old boy described the changes in his brain function using
technical and informed language which suggested an in-depth understanding of their child's disability.

"Cerebral palsy means paralysis of the brain which means in the brain. The child will be affected depending on the point of cerebral palsy. Some children will have problems with hearing, vision and intellect. Others will have difficulty in movement and mobility." M1

Conversely, most of the mothers view their child with a disability as being a normal child. Many of these mothers were noted to fluctuate between suggesting that their child was normal and that they were disabled or having difficulties.

"I prefer to classify her as a normal child. She is a very intelligent and happy girl. My daughter is normal." M2

I believe that mothers tried to focus on the normal aspects of development for many reasons. Normalcy may give them hope that their child could still be healthy and normal. The mothers were also concerned about their children’s feelings, as they assume that a child with disability would be a sensitive person and that the mother would pity him or her, and so hide the diagnosis from their children. This parental strategy influences the children’s perception of the term CP and expectations, which will be explored in depth later. This was demonstrated when I asked one of the mothers what they told their child about their condition. She spontaneously said:

"She asked many times. I always tell her that this is from her birth and that if God is willing, she will improve. I never told her that she has a disability. I also don’t like anyone to tell her about her disability." M2

There was also a strong belief that the children were experiencing delay in development. The mother of the twins preferred to believe her twins were normal and had only delayed motor development. As her twins were obviously delayed in their motor development, she kept hoping they could "catch up to their age". Her hope, however, was shattered when she was not able to see any progress with time.
"First, I thought that they were normal and they had delayed development because they were premature and twins. However, they reached one and half years and they did not walk." M3

Subtheme 2: Rejection of Term CP

The mothers felt uncomfortable with the term CP; they believed it portrayed their child negatively, which led them to reject the term CP. From the mother’s perspective, the term CP was synonymous with having an incomplete child or a child with severe mental retardation and complete paralysis throughout their whole life. The mother of a 14-year-old girl said:

"My image of people with CP was that they had severe mental retardation and were paralysed in bed their whole lives." M2

A mother of a 6-year-old boy with spastic quadriplegia justified the rejection of the term CP and tried to convince herself that her child did not have it because he was improving, at functional level. She believed that CP is a progressive disease resulting in deterioration over time with no possible improvement in his/her condition. As her child was improving he could not possibly have CP.

"I know that my child is improving with time; now he has started to talk and express himself and he has started to walk too. Cerebral palsy children will not improve over time." M6

Rejecting the term CP resulted in parents delaying seeking medical advice. A mother of a 13-year-old boy realised that her son was unable to move as easily as the other normal children. However, she remained optimistic and hoped for a better future outcome. So she did not actively seek help from the medical system at that period of time.

"I noticed that my child reached 8 months of age and was not able to sit. We (his father and herself) waited till he reached 12 months and we thought he would improve by the time." M1
Subtheme 3: The experience of Diagnosis and its Consequences

In this subtheme, the mothers spoke of their experience surrounding the diagnosis and identification or labelling of their son or daughter's impairment. The mothers mentioned that, in most cases, the families observed their children's disabilities. However, when mothers brought their suspicions to the attention of the physician, they found the physician’s response not very encouraging. Mothers were distressed with the physician's lack of sensitivity, and not providing a specific diagnosis or discussion of the risks attached with the impairment. The doctors ignored the parents' concerns about child's development which was not proceeding at an appropriate pace. The physician focussed more on problems of delayed walking or spasticity, but failed to do a holistic examination and had inadequate knowledge of CP to assess the real problem.

The mother of the twins felt distressed and powerless as her twin children were wrongly diagnosed after evaluation and treatment at several medical centres.

—We went to a local hospital and they said that they were normal. Then, we went to a private hospital for further investigations and they diagnosed them as having paralysis and then we came here.” M3

Delays in accurate diagnosis made the mothers believe that their children did not have CP. The mother of a 13-year-old girl turned down the diagnosis of CP because of the incompetence of the health professional, poor communication and lack of patience while dealing with her. She also stated that the child had been diagnosed as spastic and with delayed walking. Mothers spoke of the explanations offered by the physicians after diagnosis. They all agreed that the physicians did not have sufficient and thorough knowledge of CP which destroyed their trust. They resented the fact that the physicians in Saudi Arabia were not always frank with them, and at times gave them false assurances and hope. They also reported that the physicians did not clearly explain about the child's problem, causes and prognosis.

"The doctor did not explain the problems in detail. In the hospital near to my house, there was no meeting between the medical team and the family. They did not tell the mother what were the problems
The mothers expressed their anger and loss of trust in the physician for the delay in diagnosis, and for not taking their concerns seriously. Acknowledging the children's diagnosis is part of the process that enables mothers to make sense of their child's disability. The mother of a 14-year-old girl reported that the physicians neither examined thoroughly and carefully, nor suggested seeking a second opinion. She felt that physicians were careless or lacked knowledge of CP, which did not ensure her daughter receiving optimal medical assessment and diagnosis. She therefore felt disempowered and lack of control over the situation. She lost trust and confidence in the health professionals in Saudi Arabia forcing her to approach someone outside the country. The parents searched for explanation for their children's impairment abroad because of delay in diagnosis.

—*I took RG to the hospital in the north region, and the doctor gave us a paper to physiotherapy without any explanation. We asked him what was wrong with her, but he did not answer. Doctors said she was normal. Then, we went to Jordan and the doctor diagnosed her as cerebral palsy.*” M4

Diagnosis and prognosis are vital to manage the impairment and to access specialist support services. Thus, the mothers in this study did not have a full picture about the likely prognosis of their children's impairment. This could affect the mothers' perception of their children's disability as well as their expectation of their children's future which will be discussed in detail later. Most of the mothers had minimal expectation in the prognosis of their child. Interestingly, the mother of a 6-year-old boy said that the diagnosis had been given to her as brain atrophy, which suggested that physicians avoided using the term CP.

—*My son is a premature baby and he stayed one month in the neonatal intensive care unit; before discharge they told me that he had brain atrophy and he might not walk.*” M6

However, the picture was not always pessimistic, and some mothers also perceived the attitudes of health services and professionals as helpful. The mother of the twins had positive feelings about the healthcare profession in Saudi Arabia as she was
provided with satisfactory consultation and medical support for accurate diagnosis. She did not experience negative emotions or powerlessness when seeking help, but trusted the health professionals’ knowledge and skills. The standard of care enabled her to feel comfortable and confident with the medical system without doubting their competence.

—After seeking several hospitals in the south region we came here (RHD). My children recently were diagnosed as cerebral palsy. The physician met with us —myself and their father—and explained to us that our sons had mild cerebral palsy, and with exercises they will be able to walk.” M3

Subtheme 4: Feeling about having a Child with CP

Many mothers spoke of their frustration and disappointment on learning of the initial diagnosis of their child. Their frustration continued as they sought services for their child. All mothers held the same view as other people that a normal and physically perfect child is the only one they wanted. They never anticipated that their baby would not be physically perfect. Therefore, when the child was diagnosed with CP, they were shocked about the unexpected condition and their hope of having a healthy child was shattered, which meant that the situation was out of their control. Permanent brain damage from CP meant no hope of cure, which gave mothers a sense of foreboding for their child’s future. A mother of twins said that it was hard to face the reality of loss of her perfect sons.

—At the beginning, when I read his report, I was horrified, and I said, “No, my children are ok!” Because they wrote cerebral palsy with mental retardation, quadriplegia, delayed in speech, I asked the doctor why he did write cerebral palsy in the report, and he said that they had the mild type of cerebral palsy. I find it very difficult.” M3

All of the mothers in this study expressed their deep anguish and sorrow over the fate of their children. These feelings comprised shocked denial, grief and frustration. The mother of an 11-year-old boy cried and was shocked on hearing of the diagnosis of her child, all the more when the physician had assured her of a healthy boy.
was surprised and shocked when the doctor announced the diagnosis. I took him to the hospital and they keep saying he is normal. It hurts me — it hurts me really deeply. Just like losing my expectations.” (She covered her face and cried.) M5

Some had described the diagnosis of CP as being like “the end of the world”, because by giving birth to a disabled child she was unable to live up to social expectations of having a healthy baby. They also stated that hearing of the diagnosis was a miserable event and she tried to reject it to distance herself from the truth.

I found it very hard, and it was very difficult for me to accept. I got shocked and I felt the world was very dark by the time.” M4

Having a child with CP had a major impact on the mothers and it would be difficult to ignore the effect of that impact. The next subtheme, therefore, explores the mothers’ views of the effects of having a disabled child on their lives, and the impact on the lives of others in the family.

Subtheme 5: Mother’s Extra Caring Responsibilities

In this subtheme the mothers discussed the changes in their lifestyle and in their role as a result of increased responsibilities as a child caregiver. The mothers reported spending the majority of their time, energy, and patience in taking care of their disabled child, and having to devote themselves to the child as their children could not take care of themselves. A mother stated that their life revolved around taking care of them and in attending rehabilitation sessions. Another issue that was highlighted by the mothers was that they had less time for their husbands and their needs because so much time was spent caring for the disabled child. The mother with two disabled children reported that her role as a mother had changed significantly after her children’s diagnosis. She also reported that she allocated less time for herself, rest and entertained less than other mothers.

My life has changed a lot. I feel that there is a pressure and restriction on all of the family members — not just I. I am very stressed now. We don’t have time for recreation or fun. Having
another child with Down syndrome has put a lot of pressure on me. I don’t know why this happened to me. I don’t know. I am trying to accept the situation. I got tired. I have two children with a disability. I spent most of the time just doing childcare, attending the physiotherapy session, and fulfilling his needs. I don’t have time for myself.” M5.

Caring for a child with cerebral palsy involves a lot of physical effort for the majority of mothers. Most mothers provided varying degrees of help to their child’s personal needs such as dressing and feeding. Help with more private personal needs such as going to the toilet was also undertaken by the mothers. Mothers said that multiple physical demands were placed on them as primary caregiver for their child with CP. Increasingly as the older children became heavier they became more difficult to care for physically. In response to this the mother described exhaustion and fatigue as a result of the day-to-day stress of taking care of children with CP.

—Now AD is growing, his weight has increased. Now he weighs 50 kilos; he is very heavy. He is not helping me, and I have to carry him from the car to the wheelchair. I got tired. I can’t.” M1

Living with a child with cerebral palsy also results in great stress on all the family members. The mothers also expressed a sense of realisation that life is really hard as is managing and dealing with challenging circumstances that inevitably become part of their daily lives. One mother reported that she felt overwhelmed and had a lot of pressure and stress on her life at the beginning, but later became less stressed as she had hired a maid to help with household duties.

—My life has changed, but not that much. At the beginning I had a lot of pressure and stress, but now I have a maid who helps me.” M4

The impact of the disabled child on the mother and the family resulted in the mothers having to greatly alter their way of life to live with their children with CP whilst also trying to fulfil their domestic obligations. In Saudi culture and tradition, women are expected to join in their families' social activities which include meal
preparation and family events such as parties and weddings that traditionally continue into the early hours of the morning. Mothers felt that their social life had changed significantly; one mother reported that having a child with special needs altered their lifestyle and they have stopped attending social events with their relatives and friends. This was not only because of the child’s extra needs which were seen as a burden but also because disabled children are not accepted in the society. This will be discussed later in the community theme.

“We don’t gather socially. For 5 years, I did not go for any social gathering because of him... I stayed at home with my children and my mother and father only.” M1

Overall, the mothers considered that they had fewer opportunities, and compromised involvement in the everyday life of their society, than those who do not have disabled children. They also felt that there were additional factors that deprived them from leading their full lives. Negative public attitudes towards disability made the mother of children with CP and their families reluctant to appear in public, and visit other families, including relatives. This will be discussed in the next theme.

Theme 3: Community Attitude and Support

The third theme that emerged from the mother's data was the Community Attitude. In this theme, mothers explored the support that they receive from their family, and extended family. They also explore the wider community perception about disability and their attitude towards disabled children.

Physical disability is highly stigmatised in Saudi culture, although disabled children are generally accepted within their families, they are perceived as a sense of shame and are rejected by the community. This theme explores the consequences of negative attitudes towards the children with CP and their difficulties in coping with it. Each of the mothers spent a great amount of time talking and discussing the perceived community attitudes. They all agreed that the most difficult thing is dealing with other people’s reactions to their child. They also described how they felt that their children's visible differences created social barriers for the mothers
themselves. These social barriers included stigmatising attitudes and actions that were directed at mothers during social interactions. The mothers described responding to the discourses they had experienced by expressing feelings of inadequacy about having produced a child with disabilities and anxiety about devaluing interactions with others.
Within this theme, four subthemes were also identified: social support, blaming mothers, stigmatisation, and social isolation.

**Subtheme 1: Social Support**

This subtheme refers to assistance that mothers of children with CP receive from different resources including help from the father and other relatives for caring and treating their child. However, in Saudi culture it is unusual for fathers to care for normal children and even less so for children with disability. The main support from husbands appears to be in taking on roles outside of the home, including transporting and accompanying the child to hospital appointments. In Saudi Arabia the mother is the primary carer of the child as well as house keeper. Most Saudi families have a housemaid to help the mother with household duties. It is not the norm for fathers to provide practical help in the child's domestic care because of hierarchy of gender responsibilities. Mothers reported that in addition to their husband, they also get support from their normal children.

―My husband and my other children are very supportive. They help me with carrying them when we go out. He has stayed with us since we started the rehabilitation last month till now. He did not leave us and he applied for leave to be with us.” M3

Interestingly, a mother of a 6-year old agreed with the other mothers initially and said that her husband was very supportive; however, when I had an individual follow-up interview with her she told me the opposite and complained about lack of help and support from her husband and had a low level of involvement and responsibility in the family generally.

―My husband is not supporting me. He does not care about his child's treatment. He refused to bring me to the physiotherapy
Hiding the truth in front of other mothers could also be related to Saudi culture, as discussed earlier in Chapter 2. Family relationships are considered to be a very sensitive and private topic and are not discussed in front of non-family members. The mother also reported that she had dropped out of university and had stayed at home because she did not find her husband sufficiently supportive.

Three mothers described that they received support and assistance from other children, sisters and mother.

→MD brothers are very supportive; they helped me and took care of him.” M5

→Her sister is doing exercise for her.” M4

Although mothers receive support from their husbands, children and sisters, this was not the case with their extended family such as mothers-in-law. This will be explained in the following theme.

Subtheme 2: Blaming Mothers

Mothers are commonly blamed for their child’s disability. One mother, for example, vented her frustration over her mother-in-law’s taunt that she was the cause for her child’s disability and was not a “good” daughter-in-law, because she did not have a healthy baby. Such attitudes prevented mothers from feeling a sense of identity, belonging and caring and resulted in feelings hopeless and powerless in family relationships.

→My mother-in-law blamed me for not having a healthy child. Society blames the mother. At the beginning, my mother and my aunts told me to admit him to disabled centres and to leave him till he became independent, but I refused.” M6
Mothers also expressed feeling of shame and of receiving negative vibes from extended family towards their child. One mother of a child with spastic diplegia (wheelchair user) described stigmatising attitudes and actions that were directed at her son and herself during family social events. She said that her parents-in-law were unwilling to be seen with the child with CP.

“Also considered my husband’s family because they didn’t want me to bring him to the gathering. They told me to leave him at home and not to bring him with me, or not to come to the gathering.” M6

“My mother told me not to tell anyone from our relatives that I have a child with a disability. You know that Saudi culture thinks the cause of disability is hereditary and it is the mother’s responsibility. This may affect my sisters — they may not get married.” M6

Consistent with shame and stigma from the extended family were the mother’s experiences of negative perceptions from larger society. This will be explained in the following subtheme.

**Subtheme 3: Stigmatisation**

The mothers reported limited acceptance of their children by the society, and they were generally excluded because of lack of familiarity and knowledge about the child’s disability by public. Staring and gazing were the most common forms of stigmatisation that they experienced. It was most commonly experienced in everyday social settings. Sometimes society over-sympathises with the children with disability, which also makes them feel that they are different and are not normal. In the Saudi community, some people feel sympathetic towards disabled children because they are not as capable as other children. Some of the mothers remarked that the community should not “overly sympathize” with their disabled child or give him or her special treatment. They would prefer that their child was treated as “normal” which would help him or her to integrate into the society. For example, a mother of 11-year-old boy reported that words such as pity and sympathy were often used to describe the general community’s perception of her child. She asserted that
people shouldn’t sympathize with having a disabled child in order that they do not feel incomplete.

→ People look at him with pity and compassion, and they come close to me and they say, ‘oho, he is a pitiable boy’. I don’t like this attitude; the child will feel he is not normal. I want people to treat him like a normal child.” M5

Almost all the mothers talked about the impact of public attitudes towards disabled children and their families. The experience of stigma also resulted in feeling of powerlessness because they felt dominated by mothers who did not have disabled children. Moreover, the mothers articulated concerns that such stigma could impact their child’s self-esteem and result in psychological damage, which will be explored later in children’s themes. This powerlessness was talked about in terms of having no control over public attitude, a mother of 13-year-old girl felt powerless and helpless when she could not protect her child from the attitude shown by others.

→ To tell you the truth, I don’t accept the society attitude toward my daughter. Their attitude makes my daughter feel bad. At the same time, I can’t control the people’s attitude, and I feel powerless. The word ‘handicapped’ hurts my feelings. It hurts me a lot.” M2

Interestingly, a mother of a 14-year-old girl believed that disabled children are more openly stigmatized in Saudi Arabia compared to other Middle Eastern countries. She explained that this belief stemmed from her experience of when she visited other Middle East countries. This could be because, in general, Saudi society is devoid of disabled children and adults and therefore they are an invisible group in society, and draw attention and curiosity from other people.

→ People in Saudi Arabia see the cerebral palsy child different than others. They treat her as [an] alien, especially when she gets out in the shopping mall or at the school. I don’t like Saudis’ attitude toward the handicapped. We went to Jordan and to Kuwait, but I did not see this attitude, it was only in Saudi Arabia.” M4
Despite the fact that public attitude has a big impact on disabled children and their families, the mothers believed that they should not prevent them from being involved in society. Mothers believed that public awareness about disability was one of the main reasons for their stigma and attitude towards their children. The mothers mention that Saudi society does not have correct information or understanding of disability or children with disabilities. This is largely because children with disabilities are invisible to the public. It is very rare to see a child with walker or wheelchair in public places. Additionally, society views all disabled children as having mental dysfunction.

—*People don’t understand my children’s problems. They don’t know what is meant by physical disability. They think any person on the wheelchair is mentally retarded.”* M3

**Subtheme 4: Social Isolation**

The negative attitude from the mother-in-law and society lead to social exclusion and isolation within their own society. Many mothers purposely avoid social gatherings, preferring to remain at home, where they or their child were less likely to face discrimination. A mother of a 13-year-old boy stated that she isolated herself and stopped going outside because of the public attitude.

—*I stopped taking my children out to the shopping mall. Before I used to take them out, but I stopped because of people’s attitude toward AD. Really I found it very difficult ... very difficult. I don’t know why they behave like this.”* M1

Moreover, the lack of accessibility in public, such as streets and malls, prevented mothers from taking the child outside, which leads to more isolation. This was evident in the following:

—*I have difficulty going for outings, such as going for shopping or dining, because inaccessibility of the community. Able people don’t consider the disabled in the building structures.”* M1
8.4 Summary

The study findings are reported as three main themes for mother's focus group, which demonstrated how the mothers perceive the term –CP‖, and how their culture and religion underpin their beliefs and responses to disabilities. The findings of this study revealed that the dominant aspect shared across the data and the themes were the issues of culture, religion, and traditions related to disability that concerned both mothers and children. The data showed how the child's disability impacted the mother's daily life, and on the social activities that the families participated in their family and wider community. It was also evident that the burden of the responsibility was more likely on mothers. The mothers experienced problems with lack of support from their mother-in-law resulting in feeling isolated. This is further compounded by the negative attitude of the society. The findings also show the mother's mistrust of the medical profession whom they blame for delayed diagnosis and incorrect guidance. This complex picture had an effect on their perception of the term CP, as well as rejection and denial of their children's disability. Lastly, the findings show that the voices of the mother of the children with CP go unheard in Saudi Arabia.

The next chapter presents and explores important issues raised by children about themselves and their individual experiences.
Chapter 9: Children’s Findings

9.1 Introduction

The findings presented here are drawn from interviews with nine Saudi children and explore their experience of everyday life in their own family, school and society. The chapter is presented in two sections: the first deals with the detailed description of the participants of the study and the second the common themes that emerged from the children’s interviews.

Direct quotes are provided to support the themes identified. Anonymity and confidentiality has been maintained by allocation of codes to replace children's names.

9.2 Description of the Children

Thirteen children volunteered for the study, and four of them were excluded due to poor communication abilities. Thus, the final sample consisted of nine children with CP (three girls and six boys). The age range of the children at the time of recruitment was 5–17 years.

The children for the study were from across the Kingdom of Saudi Arabia including Central, North, South, West and East, with the highest number of participants living in Riyadh. The majority of the children were able to communicate verbally, and they did not require any assistance with communication, as they were able to express their views without assistance. Two children, however, child MA and child DH, used Talking Mats which facilitated communication and made the interview simple and understandable for their age and ability. Table 9.1 presents basic information about the nine children.
Table 9.1 Summary of children's characteristics.

<table>
<thead>
<tr>
<th>Child</th>
<th>Age</th>
<th>Gender</th>
<th>CP Type</th>
<th>GMFCS</th>
<th>School</th>
<th>Geographic Location</th>
<th>Mood of Locomotion</th>
</tr>
</thead>
<tbody>
<tr>
<td>ST</td>
<td>16</td>
<td>M</td>
<td>Spastic quadriplegia</td>
<td>IV</td>
<td>Private ordinary school</td>
<td>West</td>
<td>W/C</td>
</tr>
<tr>
<td>AN</td>
<td>17</td>
<td>F</td>
<td>Spastic diplegia</td>
<td>III</td>
<td>Private ordinary school</td>
<td>Centre</td>
<td>Walker</td>
</tr>
<tr>
<td>NI</td>
<td>9</td>
<td>M</td>
<td>Spastic diplegia</td>
<td>IV</td>
<td>Government's ordinary school</td>
<td>Centre</td>
<td>W/C</td>
</tr>
<tr>
<td>MD</td>
<td>10</td>
<td>M</td>
<td>Spastic diplegia</td>
<td>III</td>
<td>Government's ordinary school</td>
<td>South</td>
<td>Walker</td>
</tr>
<tr>
<td>HN</td>
<td>12</td>
<td>F</td>
<td>Spastic diplegia</td>
<td>I</td>
<td>Privet Ordinary school</td>
<td>Centre</td>
<td>Independent walking</td>
</tr>
<tr>
<td>AB</td>
<td>17</td>
<td>M</td>
<td>Spastic hemiplegia</td>
<td>I</td>
<td>Private ordinary school</td>
<td>Centre</td>
<td>Independent walking</td>
</tr>
<tr>
<td>DH</td>
<td>5</td>
<td>M</td>
<td>Spastic diplegia</td>
<td>IV</td>
<td>Not attending school</td>
<td>North</td>
<td>W/C</td>
</tr>
<tr>
<td>MU</td>
<td>13</td>
<td>M</td>
<td>Spastic diplegia</td>
<td>IV</td>
<td>Not attending school</td>
<td>Centre</td>
<td>W/C</td>
</tr>
<tr>
<td>MA</td>
<td>8</td>
<td>F</td>
<td>Spastic diplegia</td>
<td>IV</td>
<td>Special school</td>
<td>East</td>
<td>W/C</td>
</tr>
</tbody>
</table>

9.3 Comments on Using Talking Mats
The children included in the study had a range of communication and language skills which did have an impact upon the degree and quality of their engagement with the interviews. This factor was carefully considered at the outset of the research however, I felt that it was important to give all children the opportunity to tell me their stories. Moreover, I felt that I was able to facilitate the less able children because I had training and experience of using Talking Mats which afforded me this unique opportunity to include them. It was acknowledged however, that for the few of the children who required the use of the Talking Mats that the interviews, and their data would be simple. Of the 9 children who participated, 7 were able to respond fully to the questions asked, and provide detail and depth in their responses.
The two children who had limited verbal communication skills answered the questions with a 'yes/no' or in some cases a 'like/don't like' or short answers. Whilst this data was informative it did lack depth and richness. The following example from MA's interview illustrates the limited depth of responses.

| Sana: Ok, do you have any idea about your problem? |
| MA: Yes, My legs… (she pointed to her legs while she was talking) |
| Sana: do you know what is wrong with your legs? |
| MA: My legs are stiff … (she pointed to her legs again) |
| Sana: Do you know why your legs are stiff? |
| MA: No. I don’t know |
| I cannot walk because of my legs (she pointed to her legs) |
| I am not walking like others |
| Sana: If anyone asks you why you can't walk, what are you going to say? |
| MA: I will say , I have problem in my legs |
| Sana: Do you ask your parent why do you have problem with your legs? |
| MA: No , Because my legs like this (she pointed to her legs) |
| Sana: How do you know that you have a problem in your leg? |
| MA: Here, because I come here |

Table 9.2 Example from MA's interview.

These two children did not always respond to all the questions being asked and often offered alternative information that was not related to the questions. Therefore the questions had to be tailored for each child. Thus whilst the same questions were not always asked, the content of the questions was the same, only asked in a simplified way. The phrasing of the questions also was more focussed in order to achieve a response.

The views of the two children, with limited ability to communicate verbally, were accessed using Talking Mats. However, whilst the Talking Mat gave the children a voice and a medium through which to articulate their views but it also had limitations. The language was simple and a picture of their experiences was derived.
using pictures. The pictures also assisted in focusing the child's attention on the question being asked even when the child could communicate verbally. The following example from DH's interview illustrates the using of Talking Mats describing his daily routine.

Figure 9.1 Talking Mat describing a 5-year-old child's daily routine.

In general, the communication that occurs with younger children with greater cognitive and communication difficulties required more closed questions, from which a yes/no response is usually derived. It is also a technique which cannot explore the more social complex issues that were highlighted by the other more able children. Their limited communication may have inhibited their ability to name or describe some of the important social experiences to which the other disabled children alluded. The two children using the talking mats did not mention experiences such as discrimination and/or indicate any awareness about bullying, disability, and/or abuse. This could be because these children had not experienced it first hand, or were unaware of such negative experiences.
However, the Talking Mats did enable two children to tell me about their physical dysfunction which was similar to the descriptions provided by other children. For example, the youngest participant referred to his condition as: “I can’t walk.” While ST (16 year-old boy) described himself as “I can’t sit or stand up.”

It is acknowledged that their contributions to the findings were limited, however, it gave the children a voice, and freedom to articulate in a culture which does not engage with disabled children. Moreover, as they wanted to participate in the study and were able to contribute albeit in a limited way it would have been ethically wrong to exclude them. The findings from these two children were simple and did contribute to the study. However, they were insufficiently detailed to have an impact on the overall conclusions drawn from the work.

9.4 Children’s Themes

I followed the same process of identifying the themes for mother focus group. This process involved repeated and prolonged reading and exposure to the data. Through this process, significant statements made by the children began to emerge. All the identified themes were noted, no matter how significant or repetitive they seemed. The themes are grouped and presented in a way that I thought most encapsulated the experiences that children told me. However, links between them exist, indeed meanings and experiences related to one theme may relate to other themes. Where possible such links will be discussed.

Four themes were elicited through analysis of the data. These themes were:
Theme 1: Children’s perception and self-understanding of term ‘CP’
Theme 2: Challenges experienced at school
Theme 3: Community inclusion
Theme 4: Bullying and stigmatisation

Within each essential theme, there were several subthemes that further expressed the thematic elements of each theme and provided opportunity to examine this phenomenon in a new light. Themes and subthemes are represented in Figure 9.2.
In the following pages, I will describe each of the themes and subthemes in depth providing several examples to instantiate their meaning.

Figure 9.2 Children's themes, subthemes and categories.

**Theme 1: Children’s Perceptions and Self-understanding of the Term “CP”**

This theme focuses on disabled children's perceptions of themselves. The children were asked to give a description of the term CP in their own words. Most expressed it as mental dysfunction. It is worth mentioning that almost all the children reported that they were not used to being asked about their own experiences. For them, this study was an opportunity to express their inner thoughts that they were asked not to speak out.
They did not show any reluctance, when I asked them to take part in this study, with the exception of one child who was very quiet and did not elaborate. Nevertheless, the interview with him went on smoothly. This response from the child could be muted because such studies to understand the social world of the disabled young people seeking their views are uncommon.

Children provided a range of beliefs about disability, which contributed to their own understanding of the term disability and what it means to be a person with disability. A 17-year old girl described her understanding of the term CP.

> I believe cerebral palsy is a disorder that affects the body. The person with CP becomes disabled, and his mind will be affected. The body becomes small and will be bedridden forever, and he may understand very little." Child AN

Children emphasized that their disability resulted in physical dysfunction, but not of intelligence. This was very clear when I asked them to describe their problem". The children did not use the term –Cerebral Palsy” during the interviews, and instead described their condition as resulting from –not being to walk, having weakness, and stiffness in the legs ”. Child ST stated –I can’t sit or stand up." Child MT said –My legs are stiff”, and that –I have problem in my legs”. Child AB also described his physical disability, –I have weakness in my left side”.

This suggests that mental disability is a condition that is highly stigmatised and avoided in Saudi Arabian society. While Islamic norms dictate that kindness and care be given to the mentally ill, Arab social norms tend to approach mental illness with fear and social avoidance. Therefore disclosure of mental or intellectual disability is considered to be totally shameful for the individual, his or her family, and in some instances, for his or her town. In light of this children were basically worried about how others judged them, particularly those people who were unfamiliar with it in turn resulting in denying that they had CP. All the children during interviews said that they did not have CP with the exception of one. Although the 16–year-old boy agreed with the diagnosis of CP, he chose not to disclose it to
his relatives and friends because of their misunderstanding of the term as also because he did not want to be treated differently. He was concerned that if labelled as such they might underestimate his intellectual abilities.

→Yes, I am convinced that I have CP, I have only weakness in my left side ... CP did not affect my brain, and I have normal intelligence. I don’t say that I have CP to my friends and relatives because they are not aware of the CP term ... they don’t understand what CP means. I have normal intelligence. I don’t want them to underestimate my intellectual ability.” Child AB

In spite of a lack of thorough understanding of CP, the older children used clinical and medical terminology to describe their condition. They repeatedly stated that they had spasticity, paralysis and that their physical difficulties were due to a ‘lack of oxygen’ at birth. An example was provided by a 17-year-old girl who said

→During delivery my breathing stopped and the oxygen did not reach my brain and this affects my body.” Child AN

This explanation has been provided by the mothers (Chapter 6) and repeated by the children, which indicates that the beliefs of parents have a major influence on the child’s understanding and perception of the term ‘disability”. The following sub-themes emerged from these themes:

Sub-theme 1: Parental influence on children’s perception of CP
Sub-theme 2: Perception of difference
Sub-theme 3: Children’s strategies for coping with disability
Sub-theme 4: Future perspective

Sub-theme 1: Parental Influence on Children”s Perception of CP

Parents‘ experiences, feelings, beliefs, and ways of interacting with their children’s disability influenced their children’s conceptualisation and understanding of disability. The children appear to have acquired most of their knowledge and information understanding from their parents, and they also adopt their mothers’ values and beliefs. The use of parental knowledge as a source subsequently
influenced the way in which the children made sense of their diagnosis. This influenced the child’s perception and experiences. All the children reported that they were informed about their impairments by their parents, particularly by their mothers. A 9-year-old boy said

\[\text{–My mother said that I had a lack of oxygen, and it happened during delivery.} \text{ ” Child MD}\]

The parent's beliefs therefore seemed to have had a major influence on their child’s perception of the term –CP”. This is strongly related to the findings from the mother’s focus group (Chapter 6), where the mothers rejected the term CP and tried to justify their children’s disability.

**Sub-theme 2: Perception of Difference**

Although parental belief influences children's understanding of their disability, the children were able to differentiate and evaluate their own skills and abilities and compared themselves to others. Almost all the children interviewed perceived themselves as different to others of their age. Each one had his/her personal experience of incidents to recount which confirmed this difference, and they perceived these differences in several ways such as their impairment, use of equipment and how they were treated by others. Children looked at their impairment as a factor that prevented them from moving well which, in turn, made them feel different. For example, the youngest participant explained that he was different from his sister in terms of activity of daily living and walking ability.

\[\text{–My sister wears her shoes ... but I can’t... RH (his nanny) helps me. My sister walks. She can walk alone but I can't. ” Child DH}\]

Perceptions of being different were primarily connected with feelings of having special treatment from others or of difference in the eyes of others. Different treatments could hurt and lead to low self-confidence, but sometimes it could also give an opposite reaction, for example, a 9-year-old boy experienced being different in a positive way and he felt others became jealous of him.
Adolescence is a critical period when differences could become overt and obvious leading to feeling of indignity. A 17-year-old girl teenage girl perceives herself as being different to the other girls because she has fallen short of their cultural standards of beauty. This in turn affects how the other girls act and react towards her. This girl reported that she felt that her appearance and how she physically looked made her different to the other girls. She became aware of how different her body looks in comparison to other girls, and she started to hate her body accentuating the feeling of inadequacy. She felt ashamed of her body and believed these feelings to be a natural response to how she looks, and reprehensive of how the other girls feel about her.

→The girls can sit with crossed legs ... they are slim... and you know the girls attitude. This upsets me very much. They sit with crossed legs and they hold the biscuits softly. I see myself as fat and puffy. I can’t sit crossed.” Child AN

The problem concerning physical appearance and its impact on body image was found to be more prominent amongst teenage girls than boys. The teenage girls felt more threatened and isolated because of the importance the other girls give to physical attractiveness and body image.

→I see myself as fat and puffy. I have very big hands ... I can’t sit with crossed legs. I don’t mean in front of men. I want my appearance to be nice in front of the other girls. My appearance and my looking make me very upset.” Child AN

The children were aware of how their inadequacies impacted their daily life and their inability to perform different activities makes them feel low. All the children provided a list of “things they cannot do”. All children agreed that the most difficult
daily activities were bathing, use of toilet, dressing and getting in and out of the car. Being unable to undertake these activities independently and seeking help from other family members made them perceive themselves to be “different” than their peers. When the children talk about their difficulties, they also talk about their solutions to cope and handle their difficulties. Most children stated that they managed to be independent and move around their home without help from others. Each child has developed his/her own strategies to deal with issues at home. The youngest participant said:

—RH (his nanny) helps me dress myself with my t-shirt, carries me, and puts me inside the car. She helps me when I go to the toilet, cleans me, and helps me with putting on my pants and taking them off.” Child DH

One of the teenage boys (13 year) denied that he had any problems with his daily activities; however his sister interrupted during the interview and said that he needed help in most of his daily activities. She also said that he had only just started walking and that he cannot stand up independently and was reliant on the wheelchair all the time. Interestingly, after his sister's interruption, he agreed that he had difficulties and started discussing them.

—I can’t hold anything in my hand. If I hold something, I will lose control and it will fall down. I just started walking. I walk only here in the physiotherapy department.” Child MH

The children also spent a lot of time talking about things at which they were good. This not only related to their physical abilities, but also to their intellectual abilities.

—I do all my activities of daily living alone — dressing, bathing toileting, everything. I have no problem with walking. I walk long distances. I have an excellent score. I am proud of my school achievement.” Child AB

During the interviews, all children were keen to share their thoughts, daily experiences, worries or problems. The daily routines that they described were the
same as those undertaken by normal children. The youngest child shared with me his daily routine using the talking mat (Figure 9.1).

This theme has shown that the children's perception of their disability differs slightly from those of the mothers' views which tend to be considerably normal child or delayed walking.

**Subtheme 3: Children’s Strategies for Coping with Disability**

Children talked about their feelings of having a disability, their parents‘ support and their religious beliefs as factors that helped them to accept and cope with it. Interestingly, none of these nine children talked about the community, school, or friends as a source of support. Most of the children felt sad, frustrated, or angry about having disability and they also questioned themselves — why they got the disability?

A 16-year-old boy described his feeling about his disability:

> Honestly, when I was young, I did not think of my problem. However, when I reached 9 years, I started to think of my problem and I started to say to myself: ‘Why me? Why not the others? Why am I not like other children? What is wrong with me? Why am I not moving? Why me from all these people in the world? Why am I not walking? Why did the injury happen to me?’ All were thoughts inside me, between me and myself. I never said it to anyone.” Child ST

Growing used to their own limitations helped them accept their life situation. Living with a disability was something that they incorporated into their coping strategies, for example, a 13-year-old boy stated that he accepted his situation because he was born with disability and he had grown to accept it in time.

> I think if it happened now, it would affect me because anyone experiencing walking and moving would find it very difficult... for me, because it happened when I was child, it was easier because I did not experience walking and moving like others ... I get used to my situation. Injury for an adult person will be difficult because he has
to face his new life ... for me this was my life since I was child ... I think if the injury happened early, the shock will be less than when it happened for adults.” Child ST

Gender was also found to influence if the child accepted the disability. Girls were less accepting of their disability compared to boys. This was very clear when a 17-year-old girl talked about her feelings about disability; she also said although she had tried to accept her disability, it was hard for her to always remain optimistic and accept the situation.

"I always feel sad. I am very sad. I don’t know what to do. I don’t know how I will overcome my problem and the situation. I got used to my disability and I am trying to accept it, but it is difficult. I always cry. Sometimes I cry in front of my family... Sometimes I cry in my room alone.” Child AN

However, one child expressed his feelings in a positive way. When I asked a 9-year-old boy –Do you feel unhappy because you are not able to walk?” he stated he was lucky because he used a wheelchair.

"No, never, I am happy. Having a wheelchair is fun, Ohooo... Cool, friends ride me everywhere.” Child NI

The following two categories emerged from these subthemes
Category 1: Acceptance and support by family members
Category 2: Religious beliefs

Category 1: Acceptance and support by family members

Traditionally, Saudi family structure is culturally shaped to define family responsibilities towards its members. Socio-cultural norms of Saudi society dictate that family is the primary source for social support.

Similar to mothers’ findings of the focus group, all of the children perceived their disability as being accepted by their family members, particularly by their parents.
All of the children received support from their parents in several ways, including helping in daily activities, providing proper equipment, and taking them abroad for medical management.

―My parents supported me, they took me abroad when I was young, and they always provide me with the equipment I need. My parents provided me with all facilities that could help me in the activity of daily living. My parents provided me with all equipment; they even bought it from outside Saudi Arabia." Child ST

Very interestingly, the 17-year-old girl mentioned that her father helped her in bathing and dressing. This is most unusual in Saudi society because it is only the female members (mother or sisters) of the Saudi family who provide domestic care and not the father which I mentioned in the early parts of this thesis about Saudi culture (Chapter 2)

―My father always helps me when I go to the toilet. He helps me in wearing my shoes. Yes, my mother helps me and dresses me but my father helps me a lot. He also cares about me a lot. If I want to get in the car, he helps me, and if I want to wash for prayer, he helps me and he pours the water for me. In the toilet he helps me to take my pants off and he always says, 'I will not see you', and he turns his head to the other side." Child AN

A 9-year-old boy said that his father treated him differently from other siblings; however, he did not mention his disability as a reason for this special treatment.

"Yes, my father treats me differently than them (brothers and sisters). He gives me 10 Riyals as pocket money, while he gives my brothers three Riyals." Child NI

When I asked the child about the reason for this special treatment, he stated:

―No, I don’t think it is because of my disability. He (father) treated me differently because I am his dearest child. I am the oldest child for my father. All are younger than me.” Child NI
A child's ability to cope with stressful experiences can influence how they perceive their relationship with their brother and sister. A parent's attitude to their child's disability influences sibling relationship; children tend to adopt the attitudes of their parents. Sibling’s acceptance of a brother or sister with a disability depends on how the parents understand and respond to the child with a disability. Family’s conception of disability shapes the roles of individuals in the family. If disability is viewed as tragedy, family members may see themselves as victims or heroes. When parents favour one child, regardless of disability, if it is combined with (at times necessary) differential treatment of each child, there is likely to be a conflict in their relationship.

Most children felt that they were understood, supported and valued among their siblings and indicated a close attachment to them. The following account from child AN is an example of the type of the good relationship between siblings.

“They are very good. Thank God, they treat me like their daughter, not their sister. They help me a lot, and they love me a lot. They buy me many things and never ask me to pay them back. They buy from their own money and even if I ask them to take the money back, they refuse and they tell me to keep it: ‘you may need it later’.” Child AN

**Category 2: Religious Beliefs**

One of the most valued and most accessible resource for the children to support them in coping with their disability is religion. It has been highlighted in Chapter 2 how the Islamic religion and culture plays a dominant role in Saudi society. As discussed earlier in mothers focus group, Muslims are supposed to understand that all aspects of life, whether positive or negative, happy or tragic, are as per the will of the God. Parents reassured their children through religion. This was clear when I asked a 17-year-old girl how their family reacted when she cried because of her disability.

“They (parents) said this is from God. You should not cry and this is forbidden. Don’t cry because this is from God.” Child AN
Throughout the interviews, older children made references to their religious beliefs as a source of strength and acceptance. The religion is the one resource that can be found in abundance, children feel they can always find spiritual solace as long as they adhere closely to Islamic values regarding suffering, patience and reward. When I asked a 12-year-old girl about her feeling about unsteady walking, she said:

—*Yes, I will walk if the God wills.*” Child MD

However, some of the children also questioned what was happening with them. The 9-year-old boy believed his future and destiny were predetermined by God.

—*This is from God. I may walk, but this is from the God.*” Child NI

Children were thankful for their religion. They thanked God for several things such as family support, for their functional abilities and for having friends.

—*Thank God, I have close friends who help me a lot during the school. They help me in transportation. They never say ‘no’, and always offer help.*” Child ST

This theme suggested that when the child accepts his/her fate, it helps them to develop realistic expectations of their functional level and their future. However, this account differs from those of the mothers, which tends to be hoping to have a healthy and normal child.

**Subtheme 4: Future Perspective**

The children expressed hope for independence, both in their functional abilities and in having a job. The children identified several desires as well as concerns about their future. They all had a positive outlook towards future and the challenges awaiting them. However, they were fully aware that under the present circumstances with disabilities and their functional limitations, the likelihood of achieving their dreams is remote.
A 17–year-old boy has a high level of self-esteem and is very confident in his current abilities, he is confident that his intelligence will help him overcome limitations he may experience physically. He places higher value on what he is capable of mentally as opposed to focussing on what is difficult for him physically. When the children believe in themselves and see their ability without focussing on their disability it will facilitate and help in integration into society.

→ \textit{I am very confident and I accept my disability. I understand my limitations. Sometimes I feel worry about my walking pattern and walking ability. I have good intelligence. I always got high scores. I believe I could overcome my physical limitations.}” Child AB

The influence of people around children shapes young children’s wishes. This was very clear when a 5-year-old boy said that he wanted to be a doctor like his therapist.

→ \textit{I want to be a doctor like Dr. SH (physiotherapist).}” Child DH

Gender plays a big role in the children's wishes; boys wish to drive cars while girls wish to look like models. One girl said:

→ \textit{I wish I was slim and had nice and stylish hair. I want to sit with crossed legs. I want nice and soft hands. I don't want my hands. My hands are very big ... I want to have friends, get out with them, and to hold my friend's hand ... I don’t want to hold my friend's hand strongly. I want to touch their hands and their fingers.}” Child AN

The children’s perception of disability is affected by their view of self which in turn influences self-expectations and life goals. It seemed that most children had more realistic goals and an understanding of their future functional abilities when compared with their mothers' expectations. As mentioned earlier in the mother’s focus group findings, most of the mothers expected to have a normal and independent child; however, most children were independent in walking and mobility.
"I want to be able to transfer from the wheelchair to the bed, and vice versa. This is very important to me. I also want to strengthen my upper limb to allow me a propelling wheelchair. I wish I could push my wheelchair." Child ST

Children also shared with me their worries and fears, with most of them expressing their worries and fear related to physical impairments.

"I am very worried about falling. It is very worrying and embarrassing for me. I always think about how to protect myself from falling down. I don't want to feel pain and hurt my knees again." Child HN

The children considered that the physiotherapy treatment helped them to improve and maintain their functional level and ability. One of the girls stated that she improved a lot with physiotherapy. Later, she expressed her wish to go to Germany for intensive physiotherapy because she believed that it would make her walk.

"I want to go to Germany again because when I went to Germany, I was not able to walk and then I started walking alone. I remember the doctor was holding my hand. Then he released his hand and then I walked." Child AN

**Theme 2: Challenges Experienced at School**

This theme presents the findings based on the disabled children's own accounts of their experiences at school. The children and young people posed questions of importance to them, including children's attitudes, and accessibility to transport and buildings. The theme explores the challenges experienced and difficulties faced to be included in the mainstream activities of their schools, and identified the kind of obstacles they encountered.

These issues are discussed in the following subthemes:

Subtheme 1: Teacher’s attitude
Subtheme 2: Accessibility in School
Subtheme 3: Socialising and making friends and relationships

Subtheme 1: Teacher’s Attitude

The children were positive in their perceptions of teachers' attitudes. They described them through using words like "nice, helpful, encouraging, supportive, and welcoming". One 10-year-old boy made remarks about his teacher:

→"My teachers also are good, they are helpful, and we are all equal at school. But if anyone doesn’t do the homework, they ask why and they punish him.” Child MD

The children themselves showed a great interest in their studies, and they felt that they worked harder than their peers, an attitude to learning which may have made their teachers more helpful towards them. A 17-year-old boy said:

→"I like my studies because I see my future in it. I always got high scores.” Child AD

One of the obstacles that children faced is admission to school, especially those who live away from the main cities, which was expressed by a 13-year-old boy who used to live with his parent away from the main city and who missed the opportunity of school admission.

→"Parents couldn't send me to school. My father is an old man and he did not take him to school. Now I moved to Riyadh to live with sisters. My sister tried to register me but the school rejected my paper because I am older than the required age for the primary school.” Child MH

This boy's account suggested that there are considerable number of disabled children in Saudi Arabia, who still have no opportunity to go to school. It also suggested that some families believed that disabled children should not go to school. Additionally,
lack of opportunities to attend school might have contributed to greater exclusion of disabled children.

**Subtheme 2: Accessibility in School**

Accessibility and environmental barriers to inclusion in school were the subjects most frequently mentioned by children. In their comments, they noted obstacles in the accessibility of transport (school buses), school buildings and various facilities inside schools, toilets, upper floors, and sporting areas. One of the main barriers that the children reported during the interview was moving around school and in particular moving from class to class and another moving from class to schoolyard. Children mentioned that there were some physical environmental barriers in the school, such as lack of ramps. A 10-year-old boy talked about the need for assistance, either before he gets into the school or inside. He had his brother and uncle to help him.

—*Dad helps me to enter the school, and my brother carries my bag or sometimes my uncle and they go with me till I get in my classroom.*”

*Child MD*

Some children mentioned that their schools tried to accommodate their mobility needs by specially arranging classrooms on the ground floor. The inaccessibility of accommodation on the first floor and the sports' areas kept disabled children away from others, which meant that they were excluded from participation in a range of activities at school. A 17-year-old girl was disappointed because she missed some activities, including joining peers during break, which she could not access in her wheelchair.

—*I don’t go out during break. It is difficult to access the schoolyard.*”

*Child AN*

Children who use the school bus experience various difficulties, including inaccessibility. The buses are not adapted for wheelchair users and there are minimal standards of safety for them. Children mostly used their own transport when going
to school. One child used school transport and said that the school bus was accessible for him.

—My father rides me in the morning and I go back to my house by bus. There is a lifter in the bus to transfer me in and out the bus.”
Child NI

However, another child said that he did not use the school transport because it was not accessible for the wheelchairs.

—Dad drives me to school. He says I can’t go by bus. The bus is not appropriate for me. I can’t ride the bus. There is no lifter in the bus.”
Child MD

Subtheme 3: Socialising and Making Friends and Relationships

Friendship in school was one of the key problems highlighted by children. Establishing and maintaining friendship can be a challenge for disabled children. The interviews suggested that boys were able to integrate and make friends with their peers better than the girls. This speculation was supported by the children in their response to my question about friends — how did they get along with the others?”

—I don’t have any problem getting along with others. I have a unique personality. People like my personality. I have very close friends and schoolmates.” Child AB

Generally, the boys indicated that their friends offer help. They also mentioned that their peers not only cared and felt concerned about them, but also considered them to be part of the group. Such an experience increases the children’s self-confidence and facilitates inclusion into society.

"They are very kind. They help me a lot, buying some food for me during the school break. They are good." Child MD
Boys also reported that they had friends out of school, while girls suggested that this was not possible as the parents do not allow them to go out. In Saudi culture, girls mostly do not go out alone, while boys can go anywhere, with anyone, at any time. This emphasises how religious and social views about accepted gender behaviour shape the mobility and independence of disabled girls. Cultural restrictions appear to affect the friendship.

—My friends gave me their telephone number and they invited me several times to their houses but I did not go. My parents did not allow me to go.” Child HN

Sometimes, the disabled children found it difficult to have a close relationship with their fellow students. In ordinary schools, where almost all students are normal, the disabled children had trouble in developing friendship, as the majority preferred to be with classmates involved in other activities. However, disabled children themselves might lack the ability to be involved in friendship with their companions. For example, a 17-year-old girl perceived her disability to be an obstacle to make friends; she spoke about the difficulties in establishing and maintaining friendship because of her physical appearance, as a result of which she feels social rejection and social neglect.

"Unfortunately, this year I haven’t made any friends. I don’t have any friend from my class. Before, I used to have friends when I was in the primary school.” Child AN

However, the same girl mentioned that some of her classmates at primary school used to be her good friends but not anymore and as a result she now feels lonely and she doesn’t have good friends. This suggests that at a younger age, the girls were more accommodating and less worried by disability. She also suggested that regular students in her school, pursue their own interests together and he could not join them because of difference in interests.

—Before, I used to have friends when I was in the primary school. Now the girls are very different. I can’t get along with them because I am not interested in their chatting topics. They all have friends except me.” Child AN
The young teenagers were developing interests in fashion, contemporary music and becoming self-aware. Inferiority complex led to further social isolation. Moreover, she felt frustrated and found herself reluctant to develop friendship, because of her inability to socialise comfortably with others, her speech difficulties contributed curtailed communication ability and built barriers in making friends. She thought that most regular students were not ready to forge close relationship with disabled children.

"I don’t like their way and their lifestyle. They talk differently from me. They talk and chat about singers and the TV shows. I don’t like this kind of chatting. If I talk with them about different topics, they don’t listen to me. I am a very socialised person and I like to get with others. I like the people but if I want to pronounce the word, I can’t pronounce it correctly and they don’t understand me." Child AN

**Theme 3: Community Inclusion**

This theme explored the children's account of their involvement in their own communities, how they perceive their daily lives in the wider community, including their experience of service provision and accessibility. There is evidence that disabled children have encountered barriers to full social inclusion in their own community. Similar to their mothers, children identified significant obstacles to their inclusion such as obstacles in society structure with inaccessible places, non-functioning technical aids and negative attitude from society. The following two subthemes arose

Subtheme 1: Lack of community participation

Subtheme 2: Participation in sports and leisure activities

**Subtheme 1: Lack of Community Participation**

The inaccessibility of the local community was one of the crucial barriers to their participation that was identified by children. Almost all made it clear that they did
not enjoy moving in their own local community. They experienced different kinds of difficulties that meant they were unable to move freely, or to be independent in using their wheelchairs. A wheelchair user mentioned that he encountered physical barriers in accessing the street.

"I used to go to the grocery to buy what I need. I have an electric wheelchair which helped me a lot, but I have difficulty because the street is not accessible." Child ST

The children also experienced problems that meant they were unable to get out of their houses easily. The impact of physical barriers is immense, the lack of a lift, in this case, makes the outside world inaccessible for a 13-year-old boy, which prevented him from getting out from the house. This in turn impacts his family and he is reliant on them

→I don’t go out, because it is difficult. It is difficult. We live on the third floor. I need someone to carry me to the ground floor." Child MH

According to these accounts, disabled children were able to make a coherent link between the barriers to access they faced and the implications for their involvement in everyday life. For example, the boy (MH) experienced few opportunities to take part when he goes out. He suggested that he doesn’t like to go out because there is nothing for him to do outside due to lack of accessibility equipment in the public playground or the park.

→I look around and I see other kids playing and walking ... and I can’t ... I can’t do what they do. I just sit in my wheelchair. I don’t do anything... I just sit on my wheelchair and look at the people around me." Child MH

Physical barriers were also mentioned by children when they go to family gatherings or social activities. A 10-year-old boy described his feelings about having to be carried up the stairs of the building to take part in a family function.
"They (parents) put me in the car, and when we got there they carry me and put me in a chair. This was embarrassing to me, I didn’t take my wheelchair, I stayed on the chair, I did not move." Child MD

Older children encounter greater difficulties than younger ones. This may be due to them being bigger and heavier and the parents are less able to carry and lift them. This suggests that the children’s age influences the degree of inclusion and participation in social activities. This was evident from a 5-year-old boy who was young and easier to carry and move.

―I go to the playground and amusement park. I play with all games. I like the slippery dip. My sister likes the swings.‖ Child DH

This findings are similar to those of the mothers’ accounts; both mothers and children identified inaccessible environment as a barrier for inclusion. This suggests that inaccessibility of the local community might exacerbate negative feelings towards children with CP reinforcing their belief by preventing people with disabilities from participation. It also suggests that the inaccessible environment prevented them from participating in everyday activities, preventing them public appearance in their wheelchairs, which affects public attitude. This will be discussed later in the bullying theme.

**Subtheme 2: Participation in Sports and Leisure Activities**

The children were asked how they used their leisure time and to list the sort of activities they participated in. They all reported that their main interest was in watching television, playing electronic games and computer than participation in sports and physical activities. This could be related to the earlier theme of feeling isolated and not having any close friends, inaccessibility of the local environment, and their inability to walk. Children also stated that they preferred to play alone. A 9-year-old boy said:

―I stay alone. I play with the PlayStation and I watch TV.‖ Child NI
The younger children stated that they played with mothers and siblings.

→I play with my sister... She sits behind me and we cycle inside the house... I don’t go outside ... sometimes I take it to my grandmother’s house and cycle around the house."  Child DH

This suggested that normal children may not have the interest in spending any time with disabled children. They often would not play or walk with them. This also suggested that children with disability have limited contact with others of their age and they might face difficulties in expanding their friendship with normal children.

The children also seemed to view their physical impairment as barriers to participation in sports. They often compared themselves to their peers in relation to abilities. They felt that they were different to typically developing children as a result of their disability. A 17-year-old boy bemoaned that he can’t do tasks like the normal. This reflects the awareness that his physical abilities were different from those of his team mates, which he may have connected to his disability. He also reported that he experienced fatigue in addition to physical limitations which resulted in him not being able to fully participate in playing.

→I am not good in all functions that need healthy person... for example I am not good in swimming and soccer as well. I can’t compete with my friends, I don’t have their ability. I get tired easily."  Child AB

Barriers from play are repeated and stand out in children’s memory as painful because of notions of incompetence, abnormality and inferiority associated in the culture with physical disability. The sense of being physically different, as represented by differences in physical abilities, was present in other accounts. Children may underestimate their physical abilities, and excluding themselves from any leisure or sport activities. A 12-year-old girl, with mild spastic diplegia considered her way of doing things to be different and not ‘normal’. She felt that she was not fit enough to be as active as them and this physical difference excluded her
from some activities. She explained that she could not keep up when her friends ran, which she linked to her disability.

—Always I lose the competition with the girls. They catch me very easily. I don’t like to play with them. I don’t like the hide-and-seek game because I will be the loser.” Child HN

**Theme 4: Bullying and Stigmatisation**

While people with disability have often been treated well within the family, this has not always been true in the wider community. Children face various forms of discrimination and exclusion, despite the existence of specific legislation and disability laws. These legal responses appear to be inadequate, since they fail to fulfill their desired function of respecting and protecting disabled persons' rights.

The following subthemes emerged:

Subtheme 1: Physical abuse
Subtheme 2: Psychological/emotional abuse
Subtheme 3: Children’s feeling reaction to bullying

**Subtheme 1: Physical Abuse**

Children with disabilities may have some characteristics that have been identified as risk factors for victimisation, such as physical weakness or impaired social relations. The children interviewed mentioned that children in Saudi had experienced various forms of physical bullying such as pushing, beating up and ganging up against them. A prime example of this is what a 12-year-old girl described one of the incidents she experienced from a schoolmate:

—One day during the break, I was standing in the school yard then 2 girls came and they ran in front of me very quickly and one of them pushed me. I fell down and they laughed at me. Another time, a girl tripped me, then I fell down and my knees were hurt”. Child HN.
The level of disability also appeared to influence the degree of bullying experienced. Children with more visible CP experienced greater bullying and discrimination. This in turn resulted in the disabled children being ‘labelled’ as incompetent, and inferior. The disabled children were devalued because of their physical appearance and stigmatised. The wheelchair or walker could be a symbol of a handicap and children who use wheelchair or walker experience worse treatment when using mobility aids. A boy using wheelchair was subjected to humiliation by his schoolmates because of his wheelchair.

“When they see me in the wheelchair, they think I am weak and they slap me.” Child NI

Subtheme 2: Psychological/Emotional Abuse

The forms of psychological abuse included overlooking the disabled and not allowing to play, and wicked gazes and staring. A 17-year-old girl talked about the ignorance of her schoolmates because of her disability. She complained that they did not want to touch or hold her hands, and she suggested that this affected her emotionally and socially and resulted in her feeling lonely.

“Even if I try to hold one, she refuses and she will say, ‘I am afraid that you will fall down and I don’t want to be responsible.’” Child AN

This suggested that normal children always create a distance between them and the disabled which leads to exclusion from the mainstream of society, and creates difficulties in establishing friendship with others. Similar to mothers’, children state that many people looked or stared at them and made them feel uncomfortable. Children think the people gaze and stare at them because they are disabled. Their schoolmates are not familiar with disability nor seeing equipment such as the walker or wheelchair. A 17–year-old girl said that she does not like being stared at when she goes out.
Because the normal people stare and look at me. When people see me with the walker, they stare. I am the only person using a walker. I don’t like their attitude.” Child AN

Children, generally, did not understand why normal children have such negative attitude towards them.

―I wanted to ask them questions. Why they look at me like this? They may think I have mental retardation. Students during the break stare at me.” Child ST

Children felt that these attitudes became evident when they were introduced to new students who were unfamiliar with disability. However, as the normal children became more familiar with seeing and being with the disabled child their behaviour changed suggesting a lack of children presence in the Saudi society, as discussed in the mothers themes. It can be assumed that normal children are not yet aware of the rights of the disabled to be included in their own society.

A 17-year-old boy said:

―When I was at the primary school, students were talking about me, and they laughed at me. They were not good with me. But now the students have got used to me and they have accepted me. They stopped making fun of me, or mocking me. They dealt with me like a healthy boy. They don’t make fun of me, and they don’t call me disabled.” Child AB

Subtheme 3: Children“s Feelings and Reactions to Bullying

Children describe how they felt about bullying, and how they react to it and to bullies. They were bothered by the behaviour of those children who identified them solely by negative labels. Their accounts demonstrated how this treatment undermined their human dignity, individual identity and self-worth suggesting that such comments might exclude them from the mainstream of the society. Children expressed a range of emotions as a result of bullying including isolation, anger, sadness, and embarrassment.
—I feel hurt and sad when the girls do bad things to me and I also feel upset.” Child HN

The age at which one experiences being bullied will decide how they respond and deal with it; for example, a 17-year old boy tried to ignore these negative attitudes and concentrated on school achievement rather than the schoolmate’s attitude.

—Before, when I was young, it hurt me. Yes, the students’ laughs hurt me. It was very annoying to me. Sometimes, I felt frustrated because of the disability, but now I am ok. I overcame all those attitudes and behaviours. Even if someone looked at me or laughed at me, I didn’t care. I accepted the situation. Before, I felt sad when someone stared at me. I don’t bother myself with the people’s attitude; I am concentrating on my study. I am concentrating on how to improve myself in the school and outside the school.” Child AB

Although older children tried to ignore the attitude, this did not mean that they did not find their behaviour hurtful, or that their dignity was not being attacked. They gave evidence to what they found as very painful.

—I get used to their attitude but still I feel sad — and mad. Sometimes I cried because of their attitudes.” Child AN

Another solution explored by children towards bullying was to seek support or help. Children also talked about how they dealt with these attitudes. A child with spastic quadriplegia used this kind of strategy as a response to bullying and complained to the school director.

—I complained to the School director, and he talked with them.” Child MD

Some of the children suggested that these attitudes were the result of the bullies having their own personal problems. A 12-year-old girl said:
I think girls who do these bad things like teasing and bullying have a problem in their mind and they have a problem with themselves.”
Child HN

9.5 Summary

The aim of this chapter was to explore children’s understanding of the term CP, and the impact of disability on their life. The study findings are reported as four main themes for children’s interviews. The findings show that children perceive themselves different in several ways such as their impairment, use of equipment and how they were treated by others. Children talked about their daily experiences with their families. They valued the role of their parents in caring for them and in seeking to provide for all their daily needs. They also talked about painful experiences in their real, day-to-day lives, how they were disappointed by being excluded from different activities with their peers in the school and local community. Lastly, the findings show that the voice of the children with CP largely goes unheard in Saudi Arabia. Children are excluded from community participation, healthcare involvement and remain highly stigmatised in Saudi culture. The findings also reveal that the children's perception of CP and disability is strongly influenced by their parents.

In the next chapter, I will discuss the findings from the mother's focus group and children's interviews.
Chapter 10: Discussion of Findings

10.1 Introduction

This chapter aims to combine the findings gathered from the mothers’ focus group with those collected from the children’s interviews. The findings are presented in the context of the Bronfenbrenner (1989 & 2005) ecological framework, which was utilized in this study. Within this framework issues related to religious, cultural and societal factors are addressed, including how these factors have affected the mothers’ and children’s perceptions and experiences. The findings are also discussed in the context of other studies undertaken by key researchers within the field of children and disability research. Whilst the literature exploring these issues within Saudi Arabia was limited, appropriate literature from the Arabian Gulf region, Middle East and Islamic regions was used in the discussion.

10.2 The Ecological Model in the Saudi Context Based on the Study's Findings

The study findings assert that cultural and religious values act as an overarching and powerful frame for the interaction between children, mothers and their environment that enhances our understanding of the cerebral palsy term, as it enables us to focus on the above interactions. Beliefs exist both at the cultural level and in the minds of individuals. Parents, at the microsystem level, greatly influence a child's life through their beliefs regarding the cause of a disability, their ideas about the worth of a person with a disability, and their acceptance of a person with a disability. As this research shows, the relationship, interactions and interdependency between mothers and their children greatly shape each other’s perceptions and experiences. As Bronfenbrenner suggests, these proximal processes operate simultaneously between and within the different layers or systems that his model outlines. As such, parents’ beliefs about disability arise from the overarching beliefs and values of the society,
and the macrosystem critically influences and shapes the everyday experiences of
the mothers.

Furthermore, the elements of the exosystem and mesosystem levels, such as
community accessibility, school interactions between children and their peers and
healthcare professional interactions with mothers, influenced the mothers‘ and
children‘s experiences and perceptions, as illustrated in Figure 10.1. This will be
further considered and framed as a response to the research aims posed in chapter
one, by discussing the combined findings of perceptions and experiences of mothers
and their children, as they occur within and between the different interacting layers
or levels outlined in Bronfenbrenner‘s model. This shows the detailed ways in which
these processes operate to influence and shape perceptions and experiences
individually and collectively.

10.2.1 The Macro-System Influences on Mothers” Perceptions of CP

The findings of this study suggested that mothers had various cultural and religious
explanations for the causation of their children's disabilities. Some of the mothers
put a great emphasis on the role of the Evil Spirit or devil (Jinn) on the causation of
the disability of their children. This finding was congruent with religious and
cultural beliefs reported by Muslim scholars (Diken 2006b; Croot et al. 2008), who
reported within the Turkish and Pakistani studies, the Evil eye and Jinn were
highlighted to be the most cultural source of disability.

The notion of „God’s will‘ emerged prominently in the mothers‘ accounts, as it has
in other studies of cultural perceptions of disability within Muslims (Diken 2006a;
Diken 2006b; Croot et al. 2008; Raman et al. 2010; Daudji et al. 2011). Nevertheless, some important differences emerged between the current study and
other researchers findings. While the traditional notions of disability were as a result
of a punishment from God or as a gift from God (Diken 2006b; Croot et al. 2008;
Daudji et al. 2011), none of the current study participants (mothers and children)
verbalized this belief. This difference may be because of a different cultural
background; in the current study, the mothers and children originated from Saudi,
while in other studies such as Croot et al. (2008) and Daudji et al. (2011), mothers originated from south Asia, and in Diken (2006b) mothers originated from Turkey. These differences reflect the importance of avoiding generalised assumptions regarding individual values and beliefs according to membership in a cultural group. While an understanding of commonly held cultural beliefs can provide a point of departure for discussion of individual values, it becomes apparent that these values play a profound but varied role in shaping perceptions, understandings and experiences.

Although most mothers use religious and socio-cultural causal agents in their explanation for the cause of CP, the medical terminology was also constantly highlighted by them. For example, two mothers used the lack of oxygen that the baby had right after birth as a cause of the condition. This is consistent with previous research that has showed that mothers had adopted both ‘biomedical‘ and ‘traditional‘ explanations (Diken 2006b; Croot et al. 2008; Raman et al. 2010).

10.2.2 Impact of Beliefs about Disability on Mothers of Children with CP at Meso-System Level

Cultural perspectives, mixed with religious values, often lead to several courses of action, which may be attributed to cultural and societal interpretations such as rejection of the child’s disability and diagnosis, possible life outcomes for their children and looking for traditional treatment. Hence, mothers merge the biomedical diagnosis and explanation with their traditional and religious views in an attempt to cope personally and on behalf of their children with the reaction of others.

It was evident from the mothers’ findings that they reject the diagnosis of CP and justify their response by the position that their child was “normal” or identified their condition as a delayed motor development. This way, they stood up for their children against social stigmatisation. This finding is reinforced by McKeever and Miller (2004), who found that mothers would allow others to see their children’s worth in society by emphasising the child’s “normal” development, not only their disabilities. Additionally, mothers may have focused on the normal aspects of their
child’s development, which gave them hope that their child could still be healthy despite their fears. Therefore, to maintain hope, mothers denied the diagnosis because it contradicted their image of having a healthy child, and they had difficulty connecting CP with their child (Huang et al. 2010).
Figure 10.1 Bronfenbrenner’s ecology model applied in the context of Saudi Arabia.
Religious beliefs and perceiving the child as normal or with delayed motor development could be linked to the beliefs that mothers hold with regard to the possible life outcomes for their children. Mothers were convinced that their children would be cured of the condition because of their fatalistic views of their child’s disability (God’s will). Findings are also supported by recent research (Croot et al. 2008; Daudji et al. 2011), which showed that hopes for the future among South Asian and Pakistani cultures are often faith based. This is also consistent with prior research into autism, in which the parents’ beliefs about its causes have been shown to have a significant impact on their perception and understanding of their child’s disability and their own expectations for their child’s future (Mandell and Novak 2005).

Mothers’ beliefs about causes of their child’s disability may impact the family’s attitudes toward the child and possibly impact mother choices regarding service utilization and treatment options. However, Ghaly (2008) argued caution against such an approach because some parents refused treatment, especially early intervention services, because of their religious beliefs. Early intervention is crucial in most cases of CP (Turnbull 1993; Damiano 2006); consequently, parents who refuse to treat their children as a result of their religious beliefs may cause their children great harm by delaying their access to support services (Hasnain et al. 2008). However, this was not an issue with Saudi mothers, who reported that they chose rehabilitation and medical treatments, also considered folk and religious remedies, and adopted spiritual practices such as prayer and healing through the Qur’an, with faith to help their child to improve. Mothers varied in how much weight they ascribed to medical interventions as compared to alternative interventions. Two of the mothers who held strong traditional beliefs regarding the causation of the disability of their children held strong traditional treatment beliefs and valued more traditional treatment practices rather than biomedical ones. This builds a picture of the value of a more nuanced understanding of culture and disability, which avoids stereotypes and generalisations. This is also consistent with the study by Diken (2006b) that revealed mothers in Turkey used modern treatment methods by taking their child to medical professionals, and they gave more emphasis to and sought help from religious agents. Conversely, Mirza et al. (2009) reported that Pakistani families who believed that their child’s disability was due to
Religious beliefs, may serve in a positive way, as a means for the mothers to understand and cope with their child’s disability. Most mothers relied upon spiritual/religious coping, believing that they were chosen for a certain reason to raise a child with a disability, and thus would be rewarded in the next life. Accepting the child’s disability as the Will of God has been acknowledged in the literature. A phenomenological study exploring Iranian mothers’ lived experiences of having a child with mental retardation revealed that accepting “God’s will” was the most important source of comfort for the mothers and created a positive outlook (Kermanshahi et al. 2008). This was further endorsed by Raman et al. (2010), who undertook semi-structured interviews with ten Kuwaiti mothers and established that the strong religious beliefs that Kuwaiti mothers held provided them with a strategy to cope with their personal perspective on disability and their extended caregiving role. In Jordan, women found great solace in religion, and it was cited as their main coping mechanism. Most mothers saw having a child with disabilities as part of their destiny, a test from God and an opportunity to learn patience and perseverance (Mcconkey et al. 2008). In addition, Atkin and Ahmad (2000) suggested that the majority of Muslims emphasised their belief in God, whereby God was seen to have given the condition to the child and, with it, the tools with which to cope.

Gaining support from religious beliefs was also found in Western research. Sallfors and Hallberg (2003) indicated that believing in God gave parents healing powers and provided them with hope and anticipation of a better future. Moreover, spirituality has also been highlighted as a factor that increases resilience (McCubbin et al. 1997; Patterson 2002; Yates and Masten 2004). Research has indicated that spiritual beliefs and practices are significant contributors to healthy family functioning (Walsh 2009). On the contrary, Miles (2002) argued that submission to the will of God sometimes contradicts preventing or remedying a disability. His research suggested that some Muslim parents rejected treatment for certain
disabilities on the basis that the condition was intended by God and should be accepted with fortitude.

10.2.3 The Interaction between Mothers and the Extended Family at Meso-system

The people in the social support network largely influence the mothers’ understanding and acceptance of their child’s disability (Lindblad et al. 2007; Ravindran and Myers 2012). Mothers who felt supported and accepted from their extended family had a more positive view of their child’s disability than did those who experienced criticism or rejection (Ravindran and Myers 2012). Kermanshahi et al. (2008) noted that some grandparents blamed parents, especially mothers, for the child’s disability, and so did not accept the grandchild. Similarly, this study showed that the extended family, and in particular the mothers-in-law, rejected the child with CP, which reinforced negative social attitudes. Often the mother-in-law blamed the mothers for their child’s disability and also expressed negative evaluations about their grandchild with a disability. Thus, the picture of the Saudi extended family cooperating in caring for the handicapped is not a representative image of reality; this could be due to their beliefs that the child’s mother caused his or her disability. Jackson and Mannix (2004) revealed that mother-blaming was a burden for women, since they internalized this concept into their life and experienced distress due to their children’s misbehaviour or disease. This kind of social stigma could contribute to further segregation for the mothers and the disabled children.

Lack of support from the extended family also tends to have an isolating effect on the mother and child, which acts as a further stressor, as discrimination and abuse compound additional difficulties to the family (Horwath 2007). It also influences the quality of parent–child relationships (Green and Rodgers 2001). In contrast, the findings from this study asserted that close family relationships were a source of support. The mothers reported positive relationships with their husbands, and both mothers and children reported positive perceptions of the family environment. The findings are congruent with existing literature on families living with children with
disabilities (Glasscock 2000; Lin 2000; Skok et al. 2006). However, they contradict Bilgin and Kucuk (2010) and Moore's (2005) findings, which showed that mothers reported issues related to lack of support from family. In Turkey, Bilgin and Kucuk (2010) found that 44% of Turkish mothers reported that they struggled with insufficient support from the family, particularly their husbands, and thus had difficulties fulfilling their various familial roles.

Skok et al. (2006) reported that the informal support of spouses had a more positive role in mediating stress within the mothers than formal social support. Although most of the mothers in this study reported support from their husbands, none of them mentioned the role of their husbands in caregiving for their child. This suggested that mothers had the primary responsibility for caring for their children. Although, the findings indicated that husbands were supportive, the mothers assumed the main caregiving responsibility and often were solely responsible for this, which further contributed to their daily life stresses. Care giving responsibilities for mothers in Saudi society are influenced not only by gender, but also by the expectation that mothers will perform this family duty as their primary role (Chapter 2). This is consistent with a western study by Harden (2005), which reported that most fathers believed that caring was not their primary role, but rather their wives' responsibility, justified on the basis of gender differences. In contrast, mothers of children with CP in Glasscock's (2000) United States study stated that caregiving help from their husbands allowed them to have more time and energy to provide care for their children.

The importance of resilience is evident within the literature, and the development of a supportive infrastructure is essential to the family (McCubbin et al. 1997) because it can serve as a buffer to a mother's stress (Duvdevany and Abboud 2003). This, in turn, will enable the development of positive influences and help with the progression of children with disabilities (Lessenberry and Rehfeldt 2004). Duvdevany and Abboud (2003) explored the influence of social support on the level of stress and the personal well-being of Arab mothers of young children with intellectual disabilities using the Emotional Stress Perception Scale. They concluded that the informal support that mothers received from family members, relatives and friends raised their sense of well-being, and enabled them to cope with the objective and subjective difficulties associated with raising a child with special needs.
10.2.4 The Interaction between Mothers and Health Carers at Exosystem

Mothers’ interpretation of what constitutes disability impacts on their relationship with the professionals who provide interventions for their children. An important aspect of the parent-professional relationship is the professionals’ and families’ beliefs about the degree of authority each should hold. These views range from a paternalistic view that ‘doctor knows best’ to a collaborative understanding between the professional and the family. The relationship between families and professionals is significant because in many cases getting a diagnosis, as well as gaining the desired treatment, depends in part upon the quality of their communication (Kaba and Sooriakumaran 2007). This is particularly evident in Western literature that suggests that parents in the US often complain that professionals do not listen to them or take their views seriously (Ahern 2000), and they sometimes respond by seeking another doctor or by searching for treatments on their own (Christon et al. 2010). This is consistent with the current study findings, in which mothers believed that the doctors did not make enough effort to diagnose their disabled children. They claimed that doctors did not listen to them and did not give them any information about the child’s condition. The doctors’ behaviour and lack of communication made the mothers seek second and third opinions, and even resulted in some of them travelling abroad to find out about their child’s diagnosis or potential treatment. The level of assistance from professional sources is important for the family environment, as professionals who are sensitive, understanding and knowledgeable can help to promote healthy family functioning (Hornby and Ashworth 1994). When there was no diagnosis, the perception of the child by the parents was more changeable, often dominated by ‘but he looks so normal’ and ‘positive visualizations’ about the future. The experience of and satisfaction with the diagnostic process also depended on the setting, timing and level of information and the parents’ readiness for information (Graungaard and Skov 2006). These findings are important as they highlight the need for family-centred approaches, aiming to create a partnership-based approach between parents and professionals.
10.2.5 The Micro-system Influences on Children’s Perception of CP

At the micro level, the family were considered to be the closest, most powerful, most durable and most influential factor. The findings showed that the parents played various roles in children’s perception of their disability, they were considered to be key sources of information for their children, and, therefore, mothers’ perceptions may affect the child’s perception. The children in the current study followed the example of their parents; the teenage boys and girls suggested that disability had occurred because of lack of oxygen during birth. However, none of these children attributed the cause of the disability to Evil Spirit or devil (Jinn). They also did not use the term CP to describe their disability; some of them avoided using the word “disability” throughout the interview. Instead, they defined their condition as a physical dysfunction, and they perceived various causes for their impairments.

Moreover, the findings also indicated that the children's perception of their disability differed slightly from those of the mothers' views. Children did perceive their disability as an intrinsic problem, and perceived themselves as different to their peers, focusing on their defects, such as not being able to walk. Almost all the interviewees compared themselves, regardless of the level of impairment and equipment they used, with others in their age group, and their self-perception or self-image was based on their experiences of their everyday social world. They were aware of their own strengths, which can act as a protective factor for their overall self-worth, as when children know their capabilities, they can maximise what they can achieve (Shikako-Thomas et al. 2009).

10.2.6 Children’s Experience of Having CP at the Micro-system of home

Similar to their mothers, the children reported positive relationships among family members. Young children in this study reported that they had a close and warm relationship with their siblings, and spent large amounts of time playing and interacting with each other. Positive relationships with siblings could be linked to the way that the parents treat their children. Featherstone (1980) argued that siblings learn to give value to their experience of having a brother or sister with a disability by watching their parents. The strongest influence on a sibling's acceptance of a
brother or sister with a disability correlated with how the parents, especially the mother, understood and responded to the child with a disability (Featherstone 1980).

Moreover, school age children reported that their sibling helped them at school and sometimes at home. Corresponding with previous research, siblings of children with a disability were found to take on a more helping role, mostly in terms of emotional support and custodial care (Hannah and Midlarsky 2005). These positive relationships among the family are related to the structure of Saudi family, and it is part of Islamic laws and traditions. Al-Saif (1991) stated that family members in Saudi Arabia expect great loyalty from each other, and they also made much effort to maintain stable relationships.

10.2.7 Children’s Experiences at the Meso-system of School

Teachers’ attitudes toward a student influence how that student is going to feel about his or her learning experience (Alquraini 2010), and also influences the whole life of a child with a disability (Idrees and Ilyas 2012). The majority of the children in this study who attended school suggested that their teachers were pleasant and helpful. This is supported by Al-Ahmadi (2009) and (Alquraini 2012), who concluded that the teachers have positive attitudes toward educating disabled students in general education settings.

Despite this positive attitude from the teacher, the children experienced a negative attitude from their peers. The study suggests that children with CP have difficulty making friends with non-disabled peers. Developing and maintaining successful friendships relies on the individuals having the necessary social skills and ability to grasp the subtle social rules that govern social behaviour (Colver and Dickinson 2010).

Difficulty making friends was also influenced by gender. Boys were better able to integrate and make friends with their peers than girls, which further added to discrimination of disabled girls in Saudi. This finding is, however, contrary to the studies by Han and Chadsey (2004) and Matheson et al. (2007), who showed that friendship expectations toward peers with disabilities were not influenced by gender.
Negative peer attitudes are generally recognized as being a major barrier to full social inclusion at school for children and youth with disabilities. Findings suggest that children with cerebral palsy, and particularly females, experience higher levels of rejection than typically developing children (Nadeau and Tessier 2006). This relates to findings of the current study in that two girls reported feeling very different from their peers and having little contact with them outside school. They felt that they had been excluded from their peer group at an early age because they were unable to participate on equal terms in different physical environments and so did not establish deep bonds of friendship (Skär 2003). This may indicate that girls have less freedom, have limited places to visit and have more restrictions, compared to boys. One girl in this study described not being able to visit her friends because the parents would not allow her; this may play a role in restricting friendships among girls.

Moreover, gender issues were raised by mothers when they talked about their children's future; they assumed that a disabled daughter would not marry, which added to her feelings of being devalued. In contrast, it was assumed that boys would have marriage potential. Gerschick (2000) noted that even though disabled boys and girls may share experiences of feeling devalued, isolated, marginalized and discriminated against, disabled girls experienced additional stigma in relation to marriage and being able to produce healthy children (Gerschick 2000). Consideration of gender differences suggests that male coping and interpersonal styles may be protective for their sense of self, whereas the female style of interacting may lead to an increased risk of rejection. These findings are important as they highlight the differential support requirements of males and females and suggest that professionals should be aware of these differences so that they can more effectively support children in dealing with peer relationships.

Bullying at school was a significant issue raised by some of the children, and this occurred with non-disabled peers. Bullying was seen as one aspect of being perceived as different by others and is linked to peer rejection. This observation is supported by other literature (Connors and Stalker 2003; Lunde et al. 2006; Lindsay and McPherson 2012) that showed that children and young people who do not 'fit into' the status quo because of gender, ethnicity, and disability are likely to be
bullied. Evidence suggests that good quality friendships are a protective factor against bullying; hence, social exclusion becomes a vicious circle (Kent 2003; Konarska 2007; Lindsay and McPherson 2012).

Children in the study did not participate in any school activities because they saw themselves as less competent than their peers. This finding is reinforced by a systematic review that concluded that children with cerebral palsy may feel less competent in areas such as athleticism, scholastic ability and social achievement; however, they do not differ from typically developing children in the perception of their global self-worth (Shields et al. 2006; Shields et al. 2007). Existing literature on social interactions between children with disabilities and their typically developing peers supports the claim that children with disabilities are less often included in interactive play activities compared to their peers without disabilities. In addition, existing literature suggests that the type and severity of children's disabilities may affect interactions, implying that children who have more severe disabilities are usually less preferred playmates compared to children with less severe disabilities (Diamond and Stacey 2000). Nevertheless, the children in this study (even with mild CP) did not appear as preferred playmates by their peers without disability at school. There are a number of reasons why children with CP find it difficult to participate in sports or school activities, such as the risk of harm to self and the structure of the school building. Although such obstacles made them feel disappointed, they remained calm and resilient in the face of such obstacles as they did not have any choice other than to exclude themselves from the school activities. This finding is reinforced by the Baker and Donelly (2001) study, which noted that school design influences disabled children's social involvement. For instance, they found that classroom seating arrangements, such as rows and squares of tables, might help disabled students to have more chance to move and take part in their peers' activities. They also found that inaccessible schools or classes prevented many disabled children's enrolments, as their parents were concerned about enlisting them in inaccessible schools.
10.2.8 Experiences at the Macro-system and and Exo-systems of the Wider Community

The notion of community plays a central role in mothers’ and children’s perceptions. Societal views of CP led to the assumption that its presence would have a detrimental impact on how children with the condition view themselves (Shields et al. 2007).

Findings indicated that cultural beliefs reinforced negative attitudes towards children with disability and their mothers. The moral system of Saudi society causes children and their mothers to feel stigmatized and lose ‘face’. Stigma against people with disabilities often includes stereotyping based on misperceptions. The finding shows that children and their mothers felt that their community watched and judged them according to underlying negative beliefs about the causes of disability. Misperceptions of children with CP and their mothers include expressions like ‘poor’ or ‘deprived’ and ‘abnormal’. These misperceptions originated in the common belief that all disabled people were permanently impaired; society regarded disabled children as needy and depicted the disability as an incurable disease (Al-Gain and Al-Abdulwahab 2002). Goodwin et al. (2000) argued that the stereotyping justifies power relationships in social settings as individuals believe that power is earned through skills and abilities.

Additionally, physical disability or differences also play a role in increased stereotyping (Brewer 1988). When the individuals in a category or group are unknown or unfamiliar, people have a greater tendency to judge based on stereotypic generalizations (Brodt and Ross 1998). In this study, it seems that non-disabled people tend to problematise children with CP and categorise them as ‘the other’, in ways that exclude them and create categories that do not necessarily recognise them as people. This behaviour (the concept of ‘othering’) may drive the stigmatised child away from ‘normal’ society and lead to negative psychological consequences including shame, depression, reduced self-esteem, social isolation and reduced life-chances (Link and Phelan 2001). It was evident that the mothers and children in the study painfully tolerated the impact of societal rejection because of disability. Most of the mothers did decrease visits to the community rather than face
reactions that were difficult for them and their children to bear. This finding is reinforced by a very recent study by Azar and Badr (2006) who noted that extreme social isolation experienced by families with children with disabilities in Lebanon was due to the social stigma of disability. This was further echoed in Qatar, where mothers expressed that the impact of stigma attached to disability impacted each family member of a child with a disability and affected their disabled child emotionally, mentally, socially and academically (Kay 2011).

Mothers believed that the lack of community and public awareness could be the reason for stigmatisation in Saudi Arabia. These views were supported by a report published by the Japan International Cooperation Agency (2002), which illustrated a lack of public awareness and asserted that public attitudes are based on sympathy and social pity, which in turn increased the exclusion of disabled people from mainstream society in Saudi Arabia.

At the exosystem level, environmental barriers influence a child's view of themselves. Many children in this study hold a positive self-image; however, when environmental barriers highlight their impairment this image can become more negative (Connors and Stalker 2003; Skär 2003). Inaccessibility, environmental and structure barriers were some of the main struggle areas of children and their mothers and their accounts of segregation. When a child with impairment cannot enter a building, a kind of social exclusion and stigmatization can begin in terms of revealing his/her inability.

Children in this study identified several environmental barriers; for example, they regarded school buses as unsafe, inaccessible, and unsuitable to transport them and their wheelchairs. Similarly they reported further difficulties in the classrooms, which had insufficient space to manoeuvre a wheelchair and a lack of accessible chairs. Such difficulties also applied to external environments such as shops, food outlets, and leisure facilities. Inaccessibility increased the children's dependency on others and resulted in feelings of isolation. Saudi society discriminates against these individuals, such as ignoring them in public and preventing them from upholding their rights like other individuals do (Alquraini 2012; Alsaif 2008). Alsaif (2008)
noted that 75.3% of disabled persons in Saudi Arabia have experienced some level of discrimination in society in terms of existing architectural and social barriers.

Furthermore, mothers in this study talked about the need for a social club and social networking and interaction. These findings are supported by Al-Jadid (2013) and Hemdi (2010), who showed that institutions designed for persons with disabilities are largely only available in urban rather than rural areas. These kinds of discrimination appear to arise from an inadequate Saudi Arabian disability code that was passed by the Saudi government in 2000. The disability code pledged that people with disabilities were to have free access to appropriate medical, psychological, social, educational, and rehabilitation services through public agencies and also supported equal rights for individuals with disabilities in obtaining free and appropriate education and medical facilities (Disability Code SA 2004). However, these laws have not been upheld in Saudi Arabia, which has created a gap between the framework of these laws and the provision of services (Alsaif 2008; Al-Jadid 2013). This has contributed to the discrimination and stigma experienced by the children within this study.

This suggests that people in Saudi view children with disabilities according to the medical model. This is based on the stereotypic image of the person with disabilities as sick and lacking something fundamental (Scherer 2000), which creates and reinforces stereotypes in society while dominating law and public policy (Longmore and Umansky 2000; Ho 2004). Within the power structure of society and the medical model of disability, the able-bodied person is valued and the person with a disability needs to be fixed (Hehir 2002).

10.3 Summary

In this chapter, the findings of this study were discussed in relation to recent research in the field and in the context of Bronfenbrenner's ecological framework. The experience of mothers and children in Saudi Arabian culture is unique.
As demonstrated above, cultural beliefs and attitudes about disability in Saudi are largely negative and reinforce the discrimination that disabled individuals already face. Beliefs and attitudes were, for the most part, very influential in disempowering mothers and children. Due to the stigma, myths and stereotypes surrounding disability, mothers and children find themselves isolated and on the margins of society.

Finally, it should be mentioned that beliefs were not only disempowering but empowering at times. Both mothers and children used their faith as a coping mechanism.
Chapter 11: Conclusion

The preceding chapter considered the study's findings in the context of the ecological framework. This concluding chapter begins with a review of the key issues of the findings. The value of the study will be presented in terms of the distinctive contribution the research makes to the field of children's disability research. This is followed by a section discussing the implications for practice based on the findings of the study, the limitations of this study and recommendations for future research. Finally, the chapter records personal reflections on the research journey.

11.1 Key Findings

This novel study has for the first time presented the voice of children with CP and also the voice of their mothers in Saudi Arabia. It has revealed and presented their perceptions, personal experiences, and explained their own mechanisms of adapting and coping within the Saudi cultural context. The novel findings of this study are four-fold and include the influence of cultural perspectives, mixed with religious values in mothers' perceptions of the term CP; the mother's role and the challenges faced within that role; the children's opportunity to express the opinions of their world; and finally community stigmatisation and discrimination of children with CP and their mothers (summarised in Figure 11.1).
1. The influence of cultural perspectives, mixed with religious values in mothers’ perception of the term “cerebral palsy”

Mothers in this study recounted stories that suggested that the experience of dealing with their child’s disability often challenged them to draw on religious and cultural beliefs to develop an understanding of the disability. The event of learning about a child’s disability and subsequent questioning led to a re-definition of themselves, their understanding of the disability, and an exploration of how religion fitted in with these experiences.

Mothers also perceived their religion and spirituality as a positive force in their lives. In Saudi Arabia, mothers who are shocked at having a child with a disability resort to their religion to explain their children's disability, using it as a form of protection from social stigma.

Different understandings of disability and its causes and treatment exist within the context of religious values and this can lead to very different views about disability. Taking this into account, religion plays a crucial role in Saudi culture and in the understanding and interpretation of having a disabled child in one’s family or society. This understanding and interpretation could be seen as one of the most influential factors that affects the development of disability services.
2. Mother’s role and the challenges that she faces as a result of Saudi cultural obligations

The findings show how a child’s disability impacts on a mother’s daily life. Mothers demonstrated deep despair and negative feelings towards the diagnosis when they realised that their children were not normal. They described the strategies that they used to hide their children’s disability.

One of the key themes that kept occurring throughout this study was that children with CP were described by the majority of mothers as normal rather than disabled. The rejection stemmed from the belief that the disability would impact on the identity of these children and their mothers in negative ways. Dismissing the term CP or disability and stressing the word ‘normal’ were strategic actions intended to maintain the identity of children within the norm and to avoid social discrimination and exclusion from society.

Furthermore, mothers were found to view their children with CP as children who could improve their functional level and relations with others by valuing any small achievement. Paying attention to the child’s minimal progress encouraged the mother to hope for future possibilities and have a positive evaluation of the disabled child and herself in terms of the life of meaning and maternal identity and self-worth.

The Mothers felt different because of the way they were treated by individuals in society and by their extended family, the changes that occurred in their lives and the feelings that they experienced as a result of their children's diagnosis. Being blamed by a mother in-law, or asked questions by extended family members made the mothers feel that they were different from the status quo. They found themselves excluded by family and thus experienced isolation in motherhood. Mothers identified themselves as being different from other mothers with non-disabled children, so they maintained a flexible and changing distance between themselves and others over time. Mothers wished their children could be like other children, have equal opportunities and be treated as normal.

The experiences of mothers in this study demonstrated that there were several premises that needed to be acknowledged and put into practice. Based on these findings, I want to highlight the importance of taking into account the mothers’
expertise, and to argue the importance of relocating mothers within their social network and context. This will enable healthcare providers to understand the dynamic, changing and diverse character of the mothers’ expertise that is generated from the relationship between the mothers themselves and other members of society.

3. The opportunity for the children to be able to express their opinions on their world

The children in this study viewed themselves to be different from non-disabled children but did not identify themselves as disabled. They compared themselves to their peers in term of ability and social acceptance. Many of them reported that they felt different simply because they could not do what others did, in particular when they saw non-disabled children play freely, go to school every day without difficulty and have friends. They also felt that they did not have the same opportunities. Children found different ways to cope with their disability. A dominant perception was that they felt they were more accepting of their disability because they were born with it.

Findings also demonstrated that while some children enjoyed peer relationships and participating in activities, for others (particularly young girls) there was a strong sense of isolation and exclusion.

Bullying was a significant issue raised by some of the children and this occurred with non-disabled peers. Bullying was seen as one aspect of being perceived as different by others and is linked to peer rejection.

In general, children had a lot to say about their experience and they had some specific criticisms, which warranted being heard by their peers and community and treated as a valid contribution to community. The Saudi children’s willingness to participate in this study suggested that they were not listened to and/or asked about the difficulties that they experienced in their lives because of the disability. Therefore, there is a critical need to develop a better understanding of disabled children’s experiences. Talking and listening to children, with a genuine intention to
respond to their requests or ideas, and at the very least, to actively problem solve together, would lead to a greater sense of belonging and acceptance.

4. Community stigmatization and discrimination of children with CP and their mothers

Both mothers and children reported that they experienced discrimination and stigmatization. Disabled children and their mothers were made to feel different by being stared at and being unsupported by non-disabled people in their own community groups, local neighbourhood, and wider society. Both mothers and children used an avoidance strategy to protect themselves from social embarrassment and stigma. Children and mothers were reluctant to go out and participate in the community because they experienced curiosity from non-disabled members, a lack of support with looking after the disabled children and inaccessible venues. This suggests that the community was built for the needs of the majority of the community members, but not necessarily those of disabled members. This therefore limited their participation in social events and limited their opportunities to be able to socialize with their non-disabled and disabled peers. This further reinforces their invisibility within their own community and isolates them from activities that are enjoyed by their non-disabled peers. This also suggests that generally the members who are involved in decision-making within community design might lack an awareness of anti-discrimination legislation.

Children with CP need sustained participation in social activities to develop relationships, skills and competencies, and to foster their physical and psychological health. While the literature suggested that families of children with disabilities are moving towards integration into society (Forsyth and Jarvis 2002), there is still a lot of work that needs to be done in order for all children to be included in Saudi society.
11.2 Contribution to Knowledge

The present study makes a unique contribution to exposing the experiences of disabled children and their mothers in Saudi Arabia. It has given the children and their mothers a voice through which to express their feelings. The dominant discourse in Saudi Arabia and Middle Eastern countries, in the field of disability and childhood, is that disabled children (and children in general), are not given the opportunity to express their understanding of issues in the world around them.

This study also added knowledge to the literature on children with disability, and provided an important insight into the role of religion for Saudi mothers. Moreover, the conceptual frameworks applied to the data allowed an analysis of both the positive effects of constructing religious beliefs about disability and an explanation of how these beliefs were constructed.

The study also confirms and complements existing knowledge and literature regarding the social exclusion that disabled children and their parents experience from mainstream life and activities.

11.3 Implications for Practice

The key contribution of this study is that it provides a clear and comprehensive picture of the current situation of children with CP and their mothers. The findings within this study indicated that children with CP are less visible in public. It also highlighted that children with CP and their mothers believed that their "society" contributed to their disability, in restricting their daily lives. Their own accounts raised substantial issues and provided evidence that their society had failed to ensure their full inclusion, as a result of lack service provision, discriminatory attitudes, inaccessibility and lack of public awareness about children with disability. Therefore, policy-makers could learn from this experience and they can use research findings to help them to re-shape policy related to children disability.

The need of the services was one of the key issues identified by mothers, therefore this research may assist policymakers to consider providing more services and
establishing more organizations to meet the needs of people with disabilities. Policymakers must begin to address 'disability' through the lens of social barriers, not physical limitations. I suggest that disability organizations, as advocates for the rights of people with disabilities, should communicate the various needs of people with disabilities to the government and policy makers and could lead in making connections between policy-makers and people living with disabilities so that policies are built from the bottom-up.

Mothers who have experienced living with a child with cerebral palsy have developed their own ways to deal with challenging circumstances. They developed coping strategies to deal with challenging situations in order to be able to live with, and care for their child. Sharing experiences, emotions and knowledge could help new mothers come to terms with having a child with disability. Sharing experience is one of the effective ways that parents of disabled children use to deal with a challenging situation. Consequently, developing support or self-advocacy groups, will empower the mothers to be more involved and more aware of their children rights and will reinforce their ability to cope with the difficult role of raising a child with CP.

The findings indicated that mothers held strong traditional beliefs regarding the disability of their children. The beliefs they held shaped their reactions regarding seeking help or treatment practices and expectations of child recovery. Most mothers put significant emphasis on the importance of traditional treatment practices because of their strong traditional beliefs regarding the recovery of the condition of their children. These beliefs might be a barrier to having positive interactions and consequently getting successful outcomes from the rehabilitation services. Thus, understanding these beliefs would bring greater insight into the interactions between healthcare professionals and mothers and would result in more successful outcomes for children with disabilities. Outside of Saudi, the experiences and cultural beliefs surrounding CP may be useful to healthcare professionals who treat Saudi children who have seek medical advice abroad, as well as to populations with similar religious beliefs.
The findings also revealed that there is a need for healthcare professionals to re-examine how they communicate with family members and re-evaluate the style, type and amount of information they provide to mothers and children. This might in turn influence the meanings mothers and children have about disability. Healthcare professionals need to be exposed to and gain competence in communicating with patients from different cultures, in such a way that they are able to reflect sensitivity to cultural and linguistic influences, such that the clinician is able to maximize the flow of information and optimize clinical effectiveness. Healthcare professionals need to ensure that they are sensitive in their communication style. They also need to ensure that they are providing sufficient and adequate information to mothers who are trying to come to terms with their child’s condition, particularly during the early stages of diagnosis.

Findings of this study indicated that children were not involved with the medical and rehabilitation management. The child is not an outsider to passively receive final decisions from others, the child should be actively involved in the health team. Therefore, healthcare professionals in Saudi are encouraged to seek the child's opinion and assess their feelings on treatment and rehabilitation goals. Importantly, a patient and family-centred care approach is essential, not only to promote and facilitate the best possible health and functional outcomes for the child, but also to support and enhance family care-giving.

Moreover, the key findings of the study, which represent the voices and demands of the disabled and their mothers, should be clearly presented to all parties in society. This will be considered in the next section.

11.4 Plans for dissemination and implementation of the research findings

Research findings are usually presented in academic and professional terminology and arenas such as conferences and journals, to which socially excluded groups such as children with disabilities (Ward 1997) and parents of disabled children do not
generally have access. Thus they are often unaware about how their views have been interpreted and represented. Ward argues that:

“Now however, there is a recognition that people with learning disabilities are effectively disempowered by research if its findings are not accessible to them” (Ward, 1997 p.41)

Parents' awareness is important in order for children with special needs to enjoy their rights. The findings from this study showed that there is a need to promote and enhance mothers' awareness of their own rights and those of their children. This could be achieved through disseminating the research findings in Arabic language to the public. Therefore I plan to have the findings of the research disseminated as detailed below:

- Poster presentations or leaflets at international Disability Day on December 2014
- Use of the national media is an extremely effective way of reaching a wide public audience. I proposed to disseminate the key findings of this study at national or regional websites/ forum of disability or blog such as [http://daleel.gulfkids.com/](http://daleel.gulfkids.com/) and [http://m3aq.net/vb/](http://m3aq.net/vb/).

For healthcare professions and policymakers, the dissemination of the findings through presentations at local, regional and national conferences also helped to make visible the experiences of children and their mothers.

The findings of this research have to date been disseminated through a poster presentation at
- Posture and mobility Conference (10-12 July 2013) Appendix 8
- The European Academic Paediatric society conference (Nov. 2012) Appendix 9. These presentations are beginning to make the voice of children with CP and their mothers heard.

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1 Each year rehabilitation hospital at KFMC celebrate the international disability day to raise awareness about disability and to encourage inclusion of disabled people
It is further planned that the findings will be disseminated as following

- Dissemination of the study findings to therapists through departmental in-service\(^2\) on September 2014.
- Dissemination of the study findings to pediatric physiotherapy group.
- Abstract will be submitted to Partnership in Rehabilitation Conference on December 2015

Internationally, the research findings will be submitted at the World Congress of Physiotherapy 2015. In addition, dissemination of knowledge from this study will also be carried forward on a wider scale and a publication is planned for an appropriate professional based journals.

In my own practice, these findings have already made a difference to clinical practice with informal dissemination of findings on a regular basis to the local pediatric team both from the research findings and from my reading around the subject. I started to include the children with my clinical decision as much as possible. I also gave them opportunity to explore their problems during the physiotherapy sessions.

I am currently engaged in the development of children and family centered approach to the pediatric team. This approach may enable children to have a voice and engage them in their treatment plan and health conditions.

Finally, as a part of encouraging mothers and children to explore their views, several events for mothers and children have been carried out since last year such as mother’s awareness day held on March 2012 and children awareness day held on November 2013. The venue was PT department at KFMC.

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\(^2\) As part of continuous professional development, physiotherapy department at KFMC held weekly in-service
11.5 Strengths and limitations of the study

A major strength of this study was that it made the experiences of children with CP and their mothers visible by seeking their views about their lives. In particular, the views of children with CP were sought because they are generally marginalised in research and service provision.

Another significant aspect of this study was that it approached disability from a sociological and non-medical perspective, which is not common to disability research in Saudi Arabia. Therefore this research will open the door for future disability research in Saudi Arabia which looks at other components affecting the lives of people with disabilities instead of just focusing on the body and impairment.

While the study can be judged to have broadly achieved its aims, it is important to also acknowledge the limitations in the study. The study may be seen as limited to the study population, as the number of participants was small and should be treated with caution (Creswell 2003; Krueger and Casey 2009). A larger sample size would provide more information and better understanding of the phenomenon.

Another limitation pertains to the diversity of the sample obtained in this study. The interviews with the two children of who used the Talking Mats were difficult and produced thin data. However, the underlying ethos of the study was that all children have something to communicate and would be included regardless of their perceived levels of communication and cognitive abilities. So these interviews were included. However, the diversity of disabled young people was recognised, and the methods adapted accordingly (see section 7.9.4, 7.9.5 & 9.2). Researchers who view disabled children as a uniform group has been highlighted as a problem of earlier research (Lewis and Kellett 2004). Shakespeare (1998) also criticised previous research for being primarily non-disabled people discussing disability, adults discussing children. This study ensured that these people were allowed to speak for themselves, and discuss the issues that they saw as issues to them.

Moreover, given the extent of diversity within the Saudi culture and within Saudi families, findings from this study may not necessarily represent the typical
experience for all Saudi mothers. Whilst I tried to include children from all regions of Saudi Arabia, it was difficult to include mothers from the south and east parts of Saudi Arabia. The reason was mostly pragmatic, as consistent with this kind of academic research, the timeframe was limited. Each region in Saudi Arabia has its own culture and is likely to experience different attitudes by the community towards their child with a disability, which may affect how mothers perceive the disability.

Although the findings of the research study cannot be generalised to all children with CP and their mothers, the findings of this study are 'transferable' (Guba and Lincoln, 1994) or 'relatable' (Bell 1999) to other social sites that have similar features and contexts. This is synonymous to the concept of 'internal generalisation' (Gobo 2004) where the representativeness of the characteristic of a case is preferred to the representativeness of the case (Gobo 2004, p. 452). The extent and strength of this transferability is also enhanced based on the humanistic nature of the inquiry which involves understanding universal basic human phenomena such as speech, thought, emotions, moral, identity, and power. Perhaps the limitations relating to the generalisation of research findings could be overcome by pursuing further research with different and large samples.

As a female researcher conducting research in Saudi Arabia, there is a question as to whether my characteristics impacted on the data. It is possible that the boys, who made up the majority of the children sample, may have spoken more openly to a male researcher. While these issues are possible, I approached the interviews as openly as possible, and took many steps to ensure the children felt comfortable speaking to me. With the children with CP forming a highly diverse group, it would be difficult for any one individual to be the ideal researcher to talk to all of them.

This study focused on the experiences of mothers and their children with CP. However, the findings revealed that CP has an impact not only on mothers and children, but also on other family members. Future research is needed to involve all family members, particularly the father, grandparents and siblings, in an exploration of the experience of disability, creating a genuine family context. A holistic family approach will ensure all family members' voices are heard, offering a better understanding of the family's perspective on CP in Saudi Arabia. It will also be
useful to investigate the experiences of other people who deal with CP children, such as healthcare providers and teachers. This complex relationship is highlighted in Appendix 10.

Lastly, the findings indicate a difference in experiences between boys and girls in regard to friendship and inclusion in society due to cultural restrictions to women. Therefore, future studies in gender-related aspects of culture and the experiences of disability may be useful.

This project demonstrated that working with disabled children and their mothers can generate rich data, and also that these children want to participate in research. The methods used here can be adopted in the future when consulting with children, in order to gain an insight into their worlds.

11.6 Summary

The essence of this research was to give a voice to children and their mothers that are frequently ignored, particularly within disability research in Saudi Arabia. Although I can accept that there might be limitations to this study, it has provided a clear picture and a deep understanding of Saudi cultural and religious beliefs and has helped understand how people’s behaviour towards individuals with a disability is shaped. It has also contributed new findings to the field, in terms of giving mothers and children a voice.
Chapter 12: Reflection

This dissertation symbolizes a personal journey for me. The journey itself took me back to a place that was significant in my development, both from a personal and a professional point of view. There were multiple influences which motivated me to do this research, including my experiences as a paediatric physiotherapist working with children with CP, events that I witnessed and experienced, and the exposure to ‘real life’ which I had there.

12.1 Reflection on the research process

As Alvesson and Skldberg (2009), point out, critical ethnography research demands considerable and ongoing reflection. My reflection on the research process is addressed here to assist with research transparency and to allow the reader insight into the activity of interpretation as well as the research process as a whole.

During the course of this research I have attempted to adopt a reflexive stance in order to make my subjectivity explicit. I held a particular role as an ethnographer in that the research was undertaken in the area of my professional expertise (physiotherapy), within a society that held similarities to my own beliefs, and within a study site that was familiar to me. Moreover, as the sole researcher I acknowledge that my personal experiences, my particular disciplinary background, and the wider socio-cultural context of my life will influence my interpretations and constructions (Davies 2008). Reflexivity was therefore regarded as an important activity throughout the conduct of the study and Mezirow's (1998) guidance for critical reflection was drawn upon to aid this process.

Undertaking this research has necessitated an intensive process of learning for me and has expanded my academic knowledge in many areas including qualitative research and the use of diaries within social research. I made the decision to embark on research on children and disability because I was aware of some of the challenges
that disabled children and adults encounter. However, this research has given me a much deeper insight into the struggles and challenges which the participants encountered regularly. In practical terms, the experience of undertaking an extensive piece of research has widened my skills and enabled me to develop an understanding of the complexity of social research. It has also taught me to the importance of ethical participant recruitment, considerations of involvement and the practices of collecting and analysing data. It afforded me the opportunity of working in depth and intensively with vulnerable groups for whom I have become an advocate. It also made clear to me the challenges of meeting the expectations of the University and myself.

The process of reflexivity has been threaded throughout this thesis. In Chapter 1, I explained the personal motivation for undertaking this research and how my professional experiences drove me to refine the research area and to develop the research aims and questions. In the methodology chapter (Chapter 6), I began by offering an open account of my role as an insider researcher and the challenges and opportunities that such a position affords. In the methods chapter (Chapter 7), I critically reflected upon my relationship with the participants during interviews, the influence this had on the research, and how such issues were managed. Finally, in this chapter I have reflected on the research journey and the effect that it had on me, and I on it. The following section explains the advantage of my prior knowledge and skills as a paediatric physiotherapist working with children with CP in shaping the current critical ethnographic study.

12.2 Transition from clinician to researcher

It was important for me to locate myself within the research process, and to acknowledge, and be aware of, the role I played within the research context. This also included the impact the research had on me personally, not only for my own understanding, but to create a context in which others could also appreciate the evolving process and final research product. Reflexivity can be a difficult, but vital,
aspect of sensitive research. It is seen as an essential process if researchers are to explore emotional and emotive topics and situations. It is a process that is central to being able to make genuine sense of participants’ experiences, whilst also confirming/refuting current knowledge and elucidating new ideas (Rowling 1999). What is researched, and how it is researched, is undoubtedly influenced by personal stories and experiences. As such, it is essential that the researcher’s beliefs, experiences and skills are made explicit. This is done not with the intention of uncovering bias, but instead, to be used as a resource to guide data gathering and interpretation (Rowling 1999). It is also necessary to increase researcher self-awareness of their own assumptions and the role these may play (Grafanaki 1996). As such, researchers are encouraged to engage in continuous self-critique and self-appraisal and to look closely at how their experience shapes or influences the stages of the research process, and to place emphasis not on ‘looking good’, but on self-revelation (Dowling 2006).

The most effective way for me to undertake this process was through keeping a research journal. It was important for me, at the outset of my PhD candidature, to feel as if I could justify my decisions through my personal experience, and to make it clear that this was something I had considered in-depth. I wanted to be explicit from the outset that my experience was a part of who I was, and as such, it was not possible for me to disregard it whilst conducting the research. I have maintained a research journal from the very start which outlines my thought processes and decision making processes, and it also details my emotional reactions. This journal keeping has allowed me a space to record my initial reactions and decisions and to be able to look back at them and analyse the factors behind the decision that I made. It also made visible to me how my thought processes changed throughout the course of the research.

I was able to approach my doctorate with a fairly well-developed idea of what I wanted to explore. I had been told, and read, many times that it is important to choose a topic in which you have a keen interest, one that can hold your attention for the full span of your candidature, a topic driven by curiosity, rather than method (Ross and Morrison 1992; Polit and Beck 2004; Callejo Perez 2007). I knew that this topic could derive from many sources: interest, relevance to work, gaps in
literature and personal experience (Roberts 2007). At the outset of my PhD, I was concerned that it may be perceived as inappropriate for the starting point of my research to be my personal interest; however, the more I read, the more I realised that this was not the case, and that it was an acceptable place to begin (Gilbert 2001; Lowe 2007; Roberts 2007).

However, at this stage I had not yet decided how I would explore the issues that were important to me: the children and the mothers. Moreover, my earlier education had been delivered from a paternalistic medical model approach which was common to the education system in Saudi Arabia. I began my research journey from a positivist stance, where the values of the researcher and the subject under investigation were excluded as part of the process of the study. This was completely contrary to the qualitative paradigm which facilitated my development as an observer of the emotional lives of others as well as my own.

As a novice researcher, I found myself full of feelings, concerns, and emotions connected with stepping out of my familiar practiced clinical role at the beginning of the project. I experienced anxieties about the challenging nature of my research, and I was acutely aware of the gap in my research skills and the academic knowledge. I was particularly aware of the different language and thinking that was involved in qualitative methodology and its terminology. During the journey I was asked to examine what I understood to be truth, how truth may be different to others and to begin to reflect on my philosophical approach. It was at this point that I become uncomfortable with the positivist stance and realised the limitations of this approach.

One significant challenge was the process of making an informed decision about the ontological and epistemological position that I would take, and specifically the decision concerning the research paradigm in which I would locate this study. I had not discovered ontology and epistemology during my Master's degree and, consequently, was naïve to this new world with its incomprehensive terminology. It was utterly unknown to me but apparently familiar to most of my doctoral student cohort. This made me feel extremely uncomfortable for a period until, with further reading, philosophy became fascinating.
The process of settling on a research paradigm involved reflecting on my own beliefs and views of knowledge, so that I could identify my own epistemological and ontological position. In reflecting on my own philosophical position it seemed that my undergraduate and postgraduate science degrees and background in quantitative research had unknowingly ‘moulded’ me as a positivist. I had not consciously selected this position, but rather my previous experiences had only exposed me to the dominant positivism of healthcare research and practice. It took a number of months for me to explore my assumptions and familiarise myself with the variety of other ontological and epistemological positions and the different types of ethnography. By going back and forth between the literature ethnography and qualitative research and keeping a reflexive journal, I was able to make an informed choice so that the approach adopted in this study was appropriate. I became attracted to critical ethnography research because this approach is concerned with inequalities in society and focuses on positive social change. Critical ethnography researchers are interested in basic issues of social structure, power relationships and culture and how inequalities affect human behaviour (Carspecken 1996). Critical ethnography also acknowledges the cruciality of the personal standpoint of the researcher (Kincheloe and Mclaren 2005). Critical ethnography research explores and raises awareness of unequal power relationships and may lead to opportunities to challenge and change practice. This was perfect for my research interests.

I began to realize that I was changing my position and was becoming a researcher who sought to understand the perception of the term CP within the context of Saudi culture. I realized that in order to do this, I would need to be able to produce a detailed description of Saudi people, their culture and their social and religious beliefs. My role was changing to that of an ethnographic researcher. The role of an ethnographic researcher is to make inferences about what people know by listening carefully to what they say and by observing their behaviour, viewed in the context of shared values and culture (Spradley 1979). Acknowledging that I needed to actively encourage children and mothers to reveal their beliefs and experiences, I sought methods (please refer to chapter 6) that allowed me to build the necessary trust and confidence. I was aware that my behaviour and skills during each interview was influential and could have affected the relationship as well as the data generated. Part of the philosophy of the qualitative interviewing technique is that the
interviewee and interviewer are both individuals with emotion, interests and biases that affect how the research is done. Personal involvement is a great strength of the methodology, but it also creates problems that must be addressed. An interviewer has to be sensitive to his or her own biases, to the social and intellectual baggage he/she brings to the interview (Berg 2004; Rubin and Rubin 2005). People often talk extensively about their interview even if they are not invited to do explicitly by the interviewer. Thus the analysis might shed more light on the respondent's moral understanding than on the identification of principles.

In this study I conducted a range of in-depth interviews with children and two focus groups with mothers which were organised to explore a particular area of interest whilst also allowing flexibility in scope and depth (Greeff 2006). However, my experiences within the interviewing context were consistent with Schostak's (2006) observation that the emergent form of the interview can be surprising and stimulating. Certainly, a more open and flexible semi-structured interview format enabled me to notice, respond to and follow up on issues raised by interviewees, including perspectives that I, as the researcher, had not anticipated or envisaged.

Moreover, it is worth acknowledging that the topic of this research is a sensitive one. For instance, for mothers of children with cerebral palsy, sharing histories, hopes, feelings, thoughts and concerns in relation to their children was contextualised within a society that holds stereotypical attitudes towards individuals with disabilities as deficient and lesser. My interactions with the participants, as well as my approach to the data that was co-constructed as part of the research process, therefore warranted a great deal of sensitivity, empathy and respect. I remained cognisant of the point that Banister et al. (2011) make that research sets up, and is conducted within, power relationships. I hope I have conducted research ‘with’ rather than ‘on’ people.

There were times during the interview that I felt very disappointed. I felt that the children with CP were being forgotten by the people who were supposed to be the key providers of their care. I felt the children with CP were being marginalised and ignored by Saudi society. I personally had emotional responses and sympathy with children and mothers when they talked about their feelings towards disability which
I did not share with the participants at the time of the interview. All these emotions can affect the data being gathered and its interpretation. Inevitably their experiences impacted me and I reacted to certain statements and gestures in an indirect way. There were elements that needed to be addressed and considered before, during and after the research in order to understand their influences on the data. My prejudices needed to be considered so that I could later critique how they might influence the process and my understanding of the findings.

Feelings of personal discomfort, anxiety, surprise, shock or revulsion are all known to be of analytic significance in ethnographic research (Hammersley 1992). Being a Saudi woman, I was very aware of the cultural barriers of being an educated woman in the Saudi culture. I was also aware of male dominance and power issues. Therefore the thought of having to interview and interact with the children and the mothers was extremely difficult. I was afraid that they would turn me down, would not understand or be interested in my study.

Based on the theoretical underpinnings of the study and my choice of method, I feel strongly that a range of benefits to both the participants and the study as a whole arose as a result of me choosing to draw on my experiences. I felt strongly that my experiences could play a significant and beneficial role within my research and be used to enhance my understanding. Therefore, I made the decision to utilise my experiences throughout the research process: in the identification and framing of the research question, when collecting data, in discussions, and when analysing and writing results as other researchers have done (Warr 2004; Clingerman 2007). It is through these experiences that researchers gain insight and give meaning to their interpretations of the topic they are exploring, are alerted to the meanings and behaviours of those being interviewed and enable the researcher to gain intuitive insight (Hubbard et al. 2001; Perry et al. 2004; Rager 2005; Holland 2007). Knowledge is not something objective and removed from our bodies, experiences but is created through our experiences of the world as a sensuous and affective activity (Hubbard et al. 2001, p.126), as it is through our emotions that we make sense of, and relate to, our physical, natural and social worlds (Hubbard et al. 2001).
The knowledge that I had developed about the appropriateness of experiences and emotions in research fit well with the theoretical perspectives adopted for the research. I was aware that my knowledge, experiences and emotions were informing my choice of topic and approach to the research. A need to be objective and/or distanced from the research topic was neither possible nor desired. We all have knowledge and experience of different social networks and systems within our lives, and by reflecting on these experiences, and reframing it as theoretical knowledge, we can draw on our closeness and knowledge of the topic in our research process (Brannick and Coghlan 2007; Simmons 2007). That is what I decided I wanted to do.

Along with this, I found that my supervisors were another resource that was beneficial throughout the research process. The likelihood of PhD students making steady progress with their research and developing strong working relationships with supervisors is believed to be aided by shared research interests (Ives and Rowley 2005; Bradbury-Jones 2007; Murphy et al. 2007). Supervisors are seen to not only guide and assist their students, but to also offer a degree of support (Ives and Rowley 2005). They focus not only on the academic achievement or progress, but also on the whole person via being sympathetic and supportive of academic and non-academic aspects of the candidates’ lives (Murphy et al. 2007). Supervision is viewed as an effective resource for researchers undertaking sensitive research, as it provides an opportunity to receive necessary support, as well as the development of skill bases (Dickson-Swift et al. 2008). It has also been noted that there can be distinct benefits from having more than one supervisor, as they may complement each other and form a more comprehensive supervision team (Ives and Rowley 2005). I was fortunate enough to be in a situation where I was allocated supervisors who provided the aforementioned sources of support and mentoring. It was important for me throughout the research journey to feel that I was supported and was able to approach my supervisors at any stage throughout the study to gain support and advice. My supervisors formed a team that I knew I could approach at any stage with a range of needs and concerns, whether personal, academic, or emotional. I feel that it was extremely beneficial to have three supervisors, as for me, this meant that I would usually be able to get in contact with one if I needed urgent advice. Similarly, they all had an interest or passion for the research topic.
which allowed many in-depth and passionate discussions to occur and provided me with motivation and different perspectives to consider.

In working closely with experienced academic researchers within my PhD supervisory team, I have had many opportunities to learn, explore ideas and receive constructive feedback and criticism. The academic supervisory team offered guidance and critical review of the ideas and materials I presented, often with suggestions for other areas of fruitful study. In the early stage of the project, I sometimes found the experience of being the sole person driving the project forward difficult to manage. As I experienced success in recruiting participants, collecting and analysing data, I began to take ownership of the project. I began to truly enjoy the opportunities to discuss the project with involved others and look in detail at unexplored dimensions. I was able to move my understanding and knowledge to a new level. My perspective had changed. I had moved from being a solely quantitative researcher towards an ethnographic approach, while also considering a social perspective.

At the beginning of the research I had not realised how much this experience was going to change me as a person. The process of becoming part of the research clearly left an impact on my daily practice and my perspective on patients. The experience of observation and working with children and mothers brought me closer to them and their needs. I have learnt to listen carefully to what mother and child has to say rather than giving advice to them regarding the child’s condition. I believe that they have left an impact on how I view them in the future.

This emotional connection with the sensitivity of the data gathered together with the participants had never previously happened to me. My doctoral studies have had a profound effect on my way of thinking about patient care and about myself and my relationship with others. Today, I have learnt to consider my own skills, behaviour, practices and communication style towards my patients. I believe that this experience has made me a better practitioner not only in my daily clinical judgment but in learning to give the patient voice. I became sensitised to seeking and hearing the voice of the child, realising that sometimes we do not actively listen and at other times we lose the child's voice in the clamour from parents. I discerned that they
seemed to not speak when faced by adults who had authority or power and found their voices when they felt more in control.

My work experience as a paediatric physiotherapist has over time enabled me to build deeper relationships with children and mothers. This has also been a direct result of my studies which have changed me as a practicing therapist. My research has also helped me to develop a deeper understanding of the issues that they face. Whilst I feel that I now have an in-depth understanding of the issues, and am an advocate for them, I am also conscious that familiarity with content can lead to issues being missed or taken for granted. Thus I have attempted to develop a stance of retaining a critical distance whilst being familiar with the context.

12.3 Final Reflection

I have faced many challenges throughout the PhD journey. Before beginning this study my knowledge of the field of disability and children sociology was limited. I did not have any experience in researching children with disability. However, upon reading the literature related to sociology, disability and qualitative approach, I became aware of the field and felt comfortable to conduct the research.

Additionally, reading the disability studies has contributed to my thinking about disability identity and social life. It has challenged my assumptions and led me to consider ways in which the study could be emancipatory rather than pathologising. However, it is clear from the relative absence of recent and in-depth literature about the lives of disabled children that the main focus in this arena is still very much on adults. By carrying out this study, I was in a fortunate position to develop a unique and in-depth perspective on the children's research field.

Another challenge was the methodological approach and my position as a researcher. Prior to the study, I was not familiar with qualitative research terminology and philosophy such as ontology, epistemology and critical realism. Although choosing the ethnography approach was obvious, choosing the data analysis approach took me time. After several meetings and discussions with my
supervisors, as well as an advisor who has experience of ethnography approaches, I chose Carspecken's methods for the analysis. I have learned a lot about data analysis by carrying out this research. As a PhD student, I have been exposed to various theoretical perspectives and conceptual models and became more aware of how our perspectives and expectations colour our views of ourselves and our social realities. In fact, undertaking this research has consequently improved my awareness, skills in research methodology and confidence and shed light on the potential role of myself to contribute to literature in the field of children with disability.

Having experienced the data collection process and having listened to the children's and their mothers' voices, I realised the impact of culture and religion on children and mother's lives. The main thing that will stay with me is the enjoyment of talking to the children, with their vibrancy and energy. Meeting children and talking to them gave me an incentive to complete the study, because they felt so strongly that they wanted their voice to be heard, to live their lives in the same way as their peers. They wanted to eliminate the barriers from society that constantly reinforced their impairment.

Finally, conducting this research has given me the opportunity to gain experiences in the field of children with disability research, learn from the children and build good relations with the mothers. Mothers come to visit me in the hospital whenever they had an appointment, they even asked me questions about how my data collection was going and requested consultation regarding their children's lives. Throughout the PhD journey, my confidence has increased which has positively impacted on my leadership skills and my relationship with the PT department team.


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Green, S. E. (2007). —We’re tired, not sad”: Benefits and burdens of mothering a child with a disability. Social Science & Medicine, 64, 150–163.


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Pin, T. W., McCartney, L., Lewis, J., & Waugh, M.-C. (2011). Use of intrathecal baclofen therapy in ambulant children and adolescents with spasticity and


Appendices
Appendix 1: Advisory Group Report

Saudi Mothers’ Experiences of Having a Child with Cerebral Palsy (CP):
Advisory Group Report

The purpose of the advisory group

The purpose of the advisory group is to explore Saudi mothers' understanding of cerebral palsy as a condition. The findings from this will be used to inform the development of the research questions for the thesis and also to inform the development of mothers’ focus group guideline.

Participants

Three mothers participated. The three mothers are housewives who each have a maid to help them to take care of their CP child. The children’s ages ranged from 4 to 11 years. All children are diagnosed with CP. Two children are able to walk with a K-walker, and one is able to walk independently. One has a seizures disorder which is controlled by medication. Participants’ demographic data is presented in Table 1.

Table 1: Participants’ Demographic Data:

<table>
<thead>
<tr>
<th></th>
<th>Mother A</th>
<th>Mother B</th>
<th>Mother C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother’s level of education</td>
<td>Primary school</td>
<td>University</td>
<td>Primary school</td>
</tr>
<tr>
<td>Mother’s occupation</td>
<td>Housewife</td>
<td>Housewife</td>
<td>Housewife</td>
</tr>
<tr>
<td>Mother’s marital status</td>
<td>Married</td>
<td>Married</td>
<td>Married</td>
</tr>
<tr>
<td>No. of children</td>
<td>7</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>CP child age</td>
<td>7 yrs</td>
<td>4 yrs</td>
<td>11 yrs</td>
</tr>
<tr>
<td>CP child gender</td>
<td>F</td>
<td>M</td>
<td>M</td>
</tr>
<tr>
<td>Type of CP</td>
<td>Spastic quadriplegia</td>
<td>Spastic diplegia</td>
<td>Spastic diplegia</td>
</tr>
</tbody>
</table>
**Topic discussed during advisory group**

**CP diagnosis**
There was strong convergence of opinions among the three mothers regarding the term “cerebral palsy”. The three mothers rejected the title of CP.

“*My child is normal. He only complains of delayed walking. Doctors have to think about the term before diagnosis. I think it is better to replace the term with delayed motor development. It is more acceptable in our society.*” (Mother B)

**Family role/social life**
A mother stated that her social life had changed since having a child with a disability; she stopped going out for social gatherings because she cannot leave her child alone at home. The other two reported that their life had not changed much. They continued going out for social gatherings and they take their CP child with them.

The three mothers reported that having a child with special needs affects their lifestyle, for example, watching TV, spending time with their other kids, and doing house duties were affected because they focus on the child with the special needs.

“*My life has changed, for example, I don’t have time now to watch TV, or play with my other children. I hired a house maid to do the house duties because of my time I’d dedicate to my child MO.*” (Mother A)

**Father and family support**
Two mothers reported that their husband is very supportive; sometimes they helped them with the home exercise programme. The third mother did not have support from her husband; she believes that her husband does not play an effective role in her childcare. He works long hours.

**Information about child diagnosis and management**
The three mothers reported that they have great difficulty in finding information relevant to their child diagnosis (CP). All of the mothers said they had never been adequately informed about the diagnosis of their children.

“The doctor just referred him to physiotherapy. He did not tell me why and he just said he will improve by physiotherapy. He also did not give me enough information about my child’s conditions.”
(Mother C)

The three mothers were referred to physiotherapy by the diagnosing physicians. However, two of them were not aware of the PT services before their child’s diagnosis, and the third one was aware because she has another child with muscular dystrophy older than the CP child.

Attending school
One of the CP children was attending the mainstream school; however, his mother was not happy about the idea and about his performance at school. The mother believes that his performance was better when he was in the disabled children school.

Conclusion
The picture gained through mothers’ advisory group is representing both good and bad experiences. Generally, mothers rejected the term of cerebral palsy. They also don’t have adequate knowledge and information about the CP and its management.
Appendix 2: Faculty of Health and Social Science Research Ethics and Governance Committee Approval email

Dear Ms. Madi:

It is a pleasure to approve your application entitled "The perception of the term Cerebral Palsy (CP) in Saudi Arabia" in its current form for publication in the Faculty of Health and Social Science Research Ethics and Governance Committee. The comments of the reviewer(s) who reviewed your manuscript are included at the foot of this letter.

Please ensure you report any changes to the design of your study or any adverse incidents whilst undertaking the research to the Committee. Please ensure you write a final summary report when the research is complete so we can add this on our records.

On behalf of the Committee I would like to wish you every success with your research.

Please advise Glynis Flood (G.B.Flood@brighton.ac.uk) of the address and to whom we should send the governance letter and insurance cover note.

Sincerely,
Prof. Julie Scholes
Chair, Faculty of Health and Social Science Research Ethics and Governance Committee
J.Scholes@brighton.ac.uk

Reviewer(s)' Comments to Author:
Reviewer: 2
Comments to the Applicant
Thank you for giving detailed consideration to the comments made. Just a note for consistency, please make sure you put the same research project title on all the consent forms as Child A consent form has a different title to the Mother's consent form.

Thank you once again

Reviewer: 1
Comments to the Applicant
You have clarified those aspects identified in previous review. The proposal is now more coherent and focussed.

Date Sent: 30-Nov-2010
Appendix 3: King Fahad Medical City Institutional Review Board

(IRB) Study Approval

December 19th, 2010
ERRC Number: 10-025

Dear Ms. Sanaa Madi,

It is my pleasure to inform you that the External Research Review Committee, a subcommittee of the Institutional Review Board, has approved your study titled: "The Perception of the Term Cerebral Palsy (CP) in Saudi Arabia".

Please be informed that in conducting this study, you as the Principal Investigator is required to abide by the rules and regulations of the Government of Saudi Arabia and KFMC/ERRC. The approval of this proposal will automatically be suspended on December 19th, 2011 pending the reapplication to renew the approval. You also need to notify the ERRC as soon as possible in the case of:

1. Any amendments to the project;
2. Termination of the study.

Please observe the following:

1. Personal identifying data should only be collected when necessary for research;
2. The data collected should only be used for this proposal;
3. Data should be stored securely so that only a few authorized users are permitted access to the database;
4. Secondary disclosure of personal identifiable data is not allowed.

We wish you every success in your research endeavor.

Sincerely,

Dr. Mohamad AlTaamir
Head of External Research Review Committee
Institutional Review Board
King Fahad Medical City
Riyadh, KSA
Appendix 4: Recruitment Poster- English Version

The Perception of the term Cerebral Palsy (CP) in Saudi Arabia

Do you have a child with CP?

Do you have CP?

Are you caring for a child with CP?

If Yes,

You may wish to participate in the CP study.

If you have any questions or problems concerning the research, please call the researcher Sana Madi on 0504445898 or you can speak with my supervisors at the University of Brighton either Dr Mandy on 441273 643946 am86@bton.ac.uk or Dr Pountney 441825 724720 terry.pountney@southdowns.nhs.uk. I would be happy to answer any questions and look forward to meeting you.
عنوان المشروع: النظرية إلى مصطلح / معنى الشكل الدماغي
في المملكة العربية السعودية

هل ترغب بالمشاركة في دراسة عن الشكل الدماغي?

هل أنت طفل شكل الدماغي؟

هل نحن بحاجة بطفلك شكل الدماغي؟

إذا كنتم ترغبون في المشاركة، التسجيل عبر التواصل مع المشرفين في جامعتنا بواتساب أو البريد الإلكتروني. البريد الإلكتروني: am86@btton.ac.uk

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Appendix 6: Mothers Information Sheet - English Version

Invitation

My name is Sana Madi, and I am a pediatric physiotherapist at King Fahad Medical City. I am studying for a PhD at the University of Brighton. I would like to invite you to participate in a research study. Before you decide whether you agree to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

If you agree to participate, you will also be asked to sign an Informed Consent form before you participate in Study.

STUDY INFORMATION

Title: The perception of the term Cerebral Palsy (CP) in Saudi Arabia

Why am I doing this research?

I am doing this research to find out about the meaning of the term cerebral palsy. I want to know what the term means to you and to your child socially and medically.

Why am I being considered to participate in the study?

I am inviting you into the study because you have a child with cerebral palsy.
Do I have to take part?

It is up to you to decide whether or not to take part. If you decide not to, I will entirely respect your decision and, of course, it will not affect the healthcare your child receives in any way. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

If you agree to take part what will this involve?

If you agree to take part in this study, I would like you to join in a group discussion, the group will only include other mothers of children with cerebral palsy. The group size is between 6-8 mothers. The Researcher will lead the discussion. I would also like to interview your child. I will audio tape record the group discussion and the child interview so that I can listen to it after we have finished. Then I will transcribe them and then I will translate them to the English language.

Where and when will the interviews take place and how long will they last?

They could be at your home, at the physical therapy clinic or somewhere else that is quiet and private place. They could be in the evening or at weekend if that easier. I will interview you first and I may need to talk with your child at another time. Mothers focus group will last between 60 to 90 minutes, and children interview will last about 30 to 60 minutes. Refreshments will be available for the participants.
Will everything I say be kept private?

All the information you provide will remain anonymous and kept strictly confidential. All data will be kept and used only by the researcher and her supervisors. In the transcript, the participants, names as well as those people who you mention will be changed so you will not be identifiable. If you wish, I will give you a copy of the transcript so that you can be sure that I have written it accurately and that no-one in it can be identified by others. I will ask everyone attending the group to keep everything that was said during the discussion confidential. You can give as much or as little information as you wish.

What if I change my mind about taking part?

Your participation in this study is entirely voluntary and you can withdraw at any time you wish, without giving a reason all you have to do is let me know. However, if you withdraw I would ask if you would be happy for me to include any information that you give prior to leaving the group.

What are the potential benefits of the study?

There is no direct benefit to the participants, this research may help children with CP and their parents with PT services recommendations.

What should I do if I have any questions or concerns about the study?

If you have any questions or problems concerning the research, please call the researcher Sana Madi on 0504445898 or you can speak with my supervisors at the University of Brighton either Dr Mandy on 441273 643946 am86@bton.ac.uk or Dr Fountney 441825 724720 terry.pountney@southdowns.nhs.uk. I would be happy to answer any questions and look forward to meeting you.

Thank you for taking time to read this information sheet.
مواعيد للاختبارات للطلاب

أاسمه مناسب، أنا استاذ للاقتصاد الطبيعي للأطفال وطالب وتزوير في جامعة
برلين بالملحق المسعود، وارد أن أتوكل إلى المشاركة في دراسة بعنوان التأثيرة في
معنوي الشلل الدماغي في المملكة العربية السعودية. قبل أن تقرر ما إذا كنت ترغب
بالمشاركة، من المهم أن تقارات وتعري في بعض الأمور المهمة المتعلقة بالموضوع، إذا كان
هناك أي شيء غير واضح أو إذا كنت تزعم في مزيد من المعلومات يمكنك أن تسألني.
إذا قررت المشاركة في هذه الدراسة، سيطلب منك التوقيع على سبيل احتمالة الموافقة.

ماهو الغرض من هذا البصري؟

الغرض من هذا البصري معرفة معنوي الشلل الدماغي. أريد أن أعرف ماذا يعني بمقابلة
"الشلل الدماغي" الاجتماعية الطبيبية. وماهي علاقة وتذكرت مع طفاكة.

هل لا بد لي من المشاركة؟

الأمر متوقف لكل تقريبي المشاركة أو عدم المشاركة. أن المشاركة في هذا البصري هي
طوعية وعدم الرغبة في المشاركة لن يؤثر بأي شكل من الأشكال على الرعاية الطبيبة
التي يبلغها طفاكة. إذا قررت المشاركة سوف تحصل على معلومات كافية عن
البحث وسوف يطلب منك التوقيع على احتمالة الموافقة.
ماذا سيعتقدون عند موافقتكم على المشاركة؟ بعد البحث؟

إذا وافقتم على المشاركة في هذه الدراسة، سوف نشارككم في مجموعات.
سوف تتضمن هذه المجموعات أطفالًا للإطفال المصابين بالشلل الدماغي. تحديد المجموعة 7-8 من الأطفال، وسوف تتم التحديات البائحة، وبالإضافة إلى المناقشة، سوف نقوم بإجراء مقابلات مع طفلك. سوف يتم تسجيل المناقشات والمقابلات على أتمك من الاستماع البصري لاحقًا. ثم سوف نقوم بكتابةها. بعد ذلك سوف نترجمها إلى اللغة الإنجليزية.

أين ومتى سوف تجري المقابلات وكيف تستغرق؟
سوف تكون في عيادة العلاج الطبيعي. ويمكن أن تكون في المساء أو في الصباح حسب رغبة المشاركات. سوف نتسلب المناقشة بين 1-10 دقيقة. بعد الانتهاء من المناقشة سوف نطلب مقابلة طفلك في وقت آخر. قد تستغرق مقابلة طفلك حوالي 10 إلى 15 دقيقة.

هل ستراجعي السيت في مشاركتي؟
سوف نحتفظ جميع المعلومات التي سوف تقدمتنا بسحري تامة. وسوف نستخدم البيانات مع قبل البداية والمشارفون على فقط. السجلات البحثية وآسياء وكوابل المشاركات ستكون سريحة، وسوف يتم للمشاركات بإسماء مستعار أو رمز. إذا رغبت في قراء النص ساعدنا على النص بدينك يمكننا أن نتأكد من ذكر المعلومات المكتوب. أيضًا سوف نطلب من جميع المشاركات في المجموعات النهاية على سيت كله ما قبل حلول المناقشة. يمكنك إعطاء المعلومات كثيرة أو قليلة كما يحلل لك.
إذا لو غيرك رأيك عن المشاركة؟
مشاركةكم في هذه الدراسة هي طريقة نمطية، ويمكنك الإنسحاب في أي وقت شئت، دون إعطاء سبب، كلما عملت القيام بها هو إجباري بالأساس من المشاركة.

ما هي الفوائد المحتملة لهذه الدراسة؟
إن هذا البحث لم يتم تصميمه للحصول على أي فوائد عائدة للمشاركين فيه ولا يمكننا الوفاء بهدف ذلك في الدراسة العالية، ولكن من المحتمل أن النتائج المتوقعة من هذا البحث ستسع فائدة للأطفال الذين يعانون من الشيخوخة الدماغية وأولى أمورهم لعمل توصيات للخدمات الطبية مستقبلا.

إذا أفعل إذا كان لديك أي أسئلة أو استفسارات عن الدراسة؟
إذا كان لديك أي أسئلة أو مشاكل تتعلق بالبحث، برجي التحدث مع البايتكسن ساء، أو تحدث مع المشرفين في جامعات برايتون الدكتور أو الدكتور، إما على الهاتف 2211736426 أو البريد الإلكتروني am86@bton.ac.uk أو البريد الإلكتروني po.muney@southdowns.nhs.uk على تلفون 22439213 او البريد الإلكتروني po.muney@southdowns.nhs.uk.
وساكن سعيدة بالإجابة على أي أسئلة تتعلق إلى فائدة من هذه المعلومات، شكراً لأخذ الوقت الكافي لقراءة هذه المعلومات.
### Appendix 8: Mothers Consent Form- English Version

**Title of Project:** The perception of the term Cerebral Palsy (CP) in Saudi Arabia

<table>
<thead>
<tr>
<th></th>
<th>Statement</th>
<th>Please initial box</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I confirm that I have read and understand the information sheet dated... for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without any effect of my child therapy or any other treatment or care.</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>I agree to provide information to the researchers under the conditions of confidentiality set out on the information.</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>I agree to keep the contents of the focus group confidential.</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>I agree to take part in the above study</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Consent of parent (Please Print)</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Name of Researcher (Please Print)</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
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<td></td>
<td></td>
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</table>
Appendix 9: Mothers Consent Form- Arabic Version

<table>
<thead>
<tr>
<th>1</th>
<th>اقرار بالموافقة على المشاركة في الدراسة (نموذج الأمهات)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>عنوان المشروع : النظرية إلى معيّن الشلل الدماغي في المملكة العربية السعودية</td>
</tr>
<tr>
<td>3</td>
<td>الرجاء وضع علامت (✓) في المربع</td>
</tr>
</tbody>
</table>

- اؤكّد أنّي قرأت وفهمت وفقت المعلومات للدراسة المشار إليها أعلاه، وقد تمّ شرح البحث والإجراءات له، وقد أبلغت لي القرصنة للنظر في المعلومات، وطريقة الاستجابة، ويمكنني أن أسأل أي أسئلة إضافية في وقت لاحق.

- أدرك أنّي مشاركتي طويلة وسكيت إلغاء المشاركة في الدراسة في أي وقت دون إلغاء أي سبب ودون أن يؤثر ذلك على الرعاية الصحية المقدمة للاسترخاء.

- أوافق على تقديم المعلومات للباحثين وفقًا للشروط المذكورة أعلاه.

- أوافق على الحفاظ على الخصوصية في مجموعة البيانات.

- أوافق على المشاركة في الدراسة المشار إليها أعلاه.

<table>
<thead>
<tr>
<th>التوقيع</th>
<th>اسم المشارك:</th>
</tr>
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<th>التاريخ</th>
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<tr>
<th>التوقيع</th>
<th>اسم الباحث:</th>
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</table>
Children Information Sheet (4–12 years) (A)
The perception of the term Cerebral Palsy (CP) in Saudi Arabia

Hello, My name is Sana Madi, and I am a physiotherapist who helps children with disability.

I want to know your feelings about the meaning of the term cerebral palsy.

Can you help us? Talk to your mum and dad about whether you want to join in.
Where can I find out more information?

If you have any questions or problems concerning the research, please call the researcher Sana Madi on 0504445898 or you can speak with my supervisors at the University of Brighton either Dr Mandy on 441273643946 am86@bton.ac.uk or Dr Pountney 441825 724720 terry.pountney@southdowns.nhs.uk. I would be happy to answer any questions and look forward to meeting you.

Thank You!
Appendix 11: Children Information Sheet (13-18 year)- English Version

Children Information Sheet (Age 13-18) (B)

Hello there!
My name is Sana Madi, and I am a physiotherapist who helps children with disability.
You and your mother are being invited to participate in a new research project called 'The perception of the term Cerebral Palsy (CP) in Saudi Arabia. This leaflet will tell you all about the project. When you have read it, you and your parents can decide if you would like to take part.

So what is the project?
The project aims to find out all what you think about the meaning of the term cerebral palsy.

What happens if I take part?
Taking part is pretty easy and will not take up too much time.
I will arrange a time with you and with your parents to talk to me in a question and answer session. The interviews will last about 1 hour. I will ask you questions about yourself, how you see yourself, and what you understand by the term of CP.
Other things you should know

If you do not want to be a part of the study any more, even after you have filled out your form, that is okay with us. If there are any questions on your interview that you do not like and do not want to answer, you do not have to.

What do I do now?

When you have read this leaflet talk to your Mum or Dad about taking part. We have also given your parents a leaflet to tell them all about the study so you can decide together.

Where can I find out more information?

If you have any questions or problems concerning the research, please call the researcher Sana Madi on 0504445898 or you can speak with my supervisors at the University of Brighton either Dr Mandy on 441273 643946 am86@bton.ac.uk or Dr Pountney 441825 724720 terry.pountney@southdowns.nhs.uk. I would be happy to answer any questions and look forward to meeting you.
Appendix 12: Children Information Sheet (4-12 year) - Arabic

Title: معلومات عن الدراسة للأطفال (عمر 4 - 12 سنة)

Section: العنوان: النظرية إلى مصطلح / معرفة الشكل الدماغي في المملكة العربية السعودية

Content: مرحباً... اسميون سناء ماضي، أنا أعضائي العلاج الطبيعي التي تساعد الأطفال الذين يعانون من الإعاقة.

Section: إريد أن أعرف تشارك حول معرفة الشلل الدماغي.

Section: تحدث مع أمك وأبيك حول ما إذا كنت تريد الانضمام في البحث.

Section: كيف يمكنك مساعدننا؟
أين يمكنك معرفة المزيد من المعلومات؟

إذا كان لديك أي أسئلة أو مسأله تتعلق بالبحث، يرجى التحدث مع الباحثين، سواءً كانونًا، أو يمكنك التحدث مع المشرفين في جامعة رايتون. الرجاء التحقق من إيماء على النموذج أو البريد الإلكتروني am86@btom.ac.uk أو البريد الإلكتروني drpoundney@btom.ac.uk.

 uglf02 يدل على البريد الإلكتروني drpoundney@btom.ac.uk، أو البريد الإلكتروني drpoundney@btom.ac.uk.

وستكون سعيدة للإجابة على أي أسئلة، اتصل بنا على لائتك.

شكرا لك!
Appendix 13: Children Information Sheet (13-18year) - Arabic Version

المعلومات عن الدراسة للأطفال (من عمر 13-18 سنة) (ب)

العنوان: النظرية إلى مصطلح / معنى الشلل الدماغي في المملكة العربية السعودية

ما هي الدراسة؟

تعرفوا على الدراسة بمرفقة، سنشرح معكم معنى الشلل الدماغي، و عبرتكم مع الشلل الدماغي.

ماذا سيحدث عند موافقتنا المشاركة بنها هذا البحث؟

المشاركين في فتية السائرين، لن تستغرق الكثير من الوقت. سوف نأخذ وقت ممكنا مع والديهم للتحدث مع، قد ستتم المقابلات حوالي ساعة، وسوف أسأل كل نموذج ننسك، وكيف تتعلم مصطلح الشلل الدماغي، و أيضاً عن تجربتك.
المعلومات الأخرى يجب أن تعرفها:
إذا كنت لا ترغب بالمشاركة، حتى بعد أن قمت بتعيين النموذج الخاص بك، لن تكون مشاركة من جانبك. ويمكنك الامتناع عن الإجابة عن أي استفسارت في المقابلة لا تجد أو لا ترغب الإجابة عليها.

ماذا فعل الآن؟
بعد قراءة المعلومات تحدث مع الديك وشاركهم بالمشاركة. إذا أوجد أي استفسار الديك منشور عن البحث حتى تتمكن من اختيار القرار معاً.

أين يمكنني معرفة المزيد من المعلومات؟
إذا كنت لديك أي استفسار أو مشاكل تتعلق بالبحث، يرجى التحدث مع الباحثين على البريد الإلكتروني am86@bton.ac.uk أو البريد الإلكتروني pountney@southdowns.nhs.uk. أو الاتصال بالเลขون 02347173431 أو البريد الإلكتروني am86@bton.ac.uk. وسأكون سعيدة للإجابة على أي استفساراتك. شكرًا لك.
Appendix 14: Children Assent form- English Version

Child Assent Form

Title of Project: The perception of the term Cerebral Palsy (CP) in Saudi Arabia

I have talked to my mum and dad and I know what you want me to do.

Please tick one of the boxes below.

Yes  □ I want to take part in this study.

No  □ I don’t want to take part in this study.

Child’s Name (Please Print)  Date  Signature

Consent of parent (Please Print)  Date  Signature

Name of Researcher (Please Print)  Date  Signature
Appendix 15: Children Consent form - English Version

Child Consent Form

Title of Project: The perception of the term Cerebral Palsy (CP) in Saudi Arabia

I have talked to my mum and dad and I know what you want me to do.

Please tick one of the boxes below.

☑️ Yes  ☐ I want to take part in this study.

☐ No ☐ I don’t want to take part in this study.

Consent of parent (Please Print)  Date  Signature
________________________________________  ____________  ____________

Name of Researcher (Please Print)  Date  Signature
________________________________________  ____________  ____________
أقرار بالموافقة على المشاركة في الدراسة (نموذج الأطفال)
عنوان المشروع: النظرية إلى معي الشلل الدماغي في المملكة العربية السعودية
لقد تحدثتك إلى أمي وأبي، وأنا أعرف ماذا نيدين مني أن أفعل؟
يرجى وضع علامتك (√) في المربع

يريد أن يشارك في هذه الدراسة
لا

التاريخ
اسم الطفل المشارك:
التاريخ
اسم والدة المشارك:
التاريخ
اسم الباحثة:
 السيطرة على المشاركة في الدراسة (نموذج الأطفال)

عنوان المشروع: النظرة إلى ممعنى الشكل الداخلية في المملكة العربية السعودية

لقد تحديتك إلى أمي وأبي، وانا أعرف ماذا تريدون مني أن أفعل

يرجى وضع علامتان (✓) في المربع

أريد أن اشارك في هذه الدراسة

لا لا أريد أن اشارك في هذه الدراسة

اسم والدة الطفل المشارك:

التاريخ

توقيع

اسم البالغ:

التاريخ

توقيع
Appendix 18: Mother’s Focus Group Transcript

Focus Group 1

Date: 29 January 2011
Site: Physical therapy department conference room. King Fahad Medical City
Time discussion started: at 9:00 a.m.
Time ended: 10:15 a.m.
Number of participants: six mothers

Sana: Thanks for coming to this meeting. I really appreciate your participation and I wish you a good time. My name is Sana and I am a paediatric physiotherapist and doctorate student studying in the UK, University of Brighton.
This is my colleague SH — she is a paediatric physiotherapist.

My research title is “The perception of the term Cerebral Palsy (CP) in Saudi Arabia”. The reason that I am interested in this study is because some mothers have suggested that the term “cerebral palsy” is not a true reflection of their children’s condition. I am interested in exploring with you your understanding of the term “cerebral palsy”. I want to know what the term means to you.

The focus group will take about one and a half hours depending on how much you have to say. I would like to audiotape our conversations. The aim of recording this session is to enable me to do the transcription of the recorded data later. Certainly, there is no wrong or right answer and you might choose to leave at any time you decide without giving a reason.
I want to assure you that this interview is confidential and completely voluntary. Your name will not be connected with the finding of our research study.
The discussion will be between me and all of you and between you and each other; I would like to ask you all to keep the confidentiality and respect the opinion of everybody here in this meeting.

You also have the right to refuse any or all questions in the interview. You do not have to answer any questions that make you feel uncomfortable. I also want to remind you that you can stop the interview at any time and this will not affect you in anyway, including the service or care that you or your child receives from the hospital.

Before we start, do you have any question about the focus group?

**Mother:** Are you going to publish this research? Can I get a copy?

**Sana:** Yes, you can. When I finish and pass the PhD study, I am going to publish it in a scientific journal; it will be in the English language. But for sure I will give you a copy of the article, or if you want a copy from this discussion, I will give it to you after transcription.

**Sana:** Would everyone introduce themselves by their first name so that it would be easy to identify your voices when I do the transcription.

M1: Um Ab
M2: Um Am
M3: Um Ha
M4: Um Rg
M5: Um Mo
M6: Um Az

**Sana:** Thanks and welcome.

**Sana:** Would you please tell me, in your own words, what the term “cerebral palsy” means to you?

**M1:** Cerebral palsy means paralysis of the brain, which means in the brain — the child will be affected depending on the point of cerebral palsy. Some children will have problems with hearing, vision and intellect; others will
have difficulty in movement and mobility. For my son, he has problems with nerves and muscles. I am not convinced that my son has cerebral palsy.

**M2:** The same thing. It means not affecting the movement, but affecting the intellectual ability. Thank God my daughter does not have cerebral palsy. I never heard about it before.

**M3:** Cerebral palsy is affecting the brain. Sometimes it has severe effects — sometimes mild or moderate. It could affect the movement, intelligence, hearing, speech, and vision. For my sons, first we thought that they were normal but they have delayed development because they are premature and twins.

**M4:** Cerebral palsy means a lack of oxygen during birth or may be due to a difficult delivery. Cerebral palsy means the brain is affected, and this may cause damage to the movement, hearing, vision, speech, and intellectual centre. It also affects the child nerves; therefore, when he grows up, the effect will become severe. The child might have a spastic or hypotonic pattern.

**M5:** The same thing. It means a lack of oxygen during birth that affects the brain cells. For my daughter the effect in the motor cells leads to an inability to walk.

**M6:** I am not convinced that my son has cerebral palsy; my son has delayed motor development. I know my child is improving by the time; now he has started to talk and express himself and he has started to walk.

**Sana:** Ok, how do you feel about the term “cerebral palsy”?

**M1:** I believe cerebral palsy is affecting the brain, and the child may have brain atrophy. From my point of view, cerebral palsy has several types. I am not convinced that my child has cerebral palsy; I am not convinced at all. My child is improving by the time; now he is 13 years and a half and he has started to stand and walk. His brain is normal. Cerebral palsy is affecting the brain.
M2: Cerebral palsy children may not walk. They may be disabled but my daughter is preterm 20 gestational weeks. She stayed 4 months in the neonatal intensive care unit, and I believe this is the cause of delayed walking. I took her to many physicians. They never said that she has cerebral palsy. She is very intelligent. She memorised half of the holy Quran.

M3: I don’t know. I did not expect that my sons have cerebral palsy. I thought it was only delayed in their movement because they are twins.

M4: I believe my daughter has cerebral palsy affecting her walking ability. Cerebral palsy does not mean mental retardation, but the motor centre in my daughter's brain is affected and making her unable to walk.

M5: I do agree with Um Rg — Mo has cerebral palsy affecting his ability to move and communicate.

M6: Cerebral palsy children will not improve by the time. My son is improving. I believe my child's brain is normal. He has only delayed growth and development. Now he has started to stand, descending and ascending stairs.

Sana: How did you know that your child has a problem?

M1: I knew from the beginning. I noticed that my child reached 8 months of age and he was not able to sit. I took him to the hospital, he had an MRI, and then the doctor told us that Ab has cerebral palsy. I went to many hospitals and centres in Riyadh to confirm the diagnosis and they said the same thing, but still I am not convinced. My son’s head was very small and now he is normal. I don’t think he has cerebral palsy.

M2: At the age of two years, I noticed that she had delayed walking and sitting. I went to the hospital and they said spasticity and delayed walking, and the doctor told us that she will improve and she will walk. No one told us that she has cerebral palsy. In the hospital near to my house, there is no meeting between the medical team and the family. They don’t tell the mother what the problems are or what the prognosis is; they just assess her and give her another appointment.
M3: I never thought that my sons have cerebral palsy; at the beginning I thought they had delayed walking. But they reached one and half years and they did not walk. We went to the hospital in the south region and they said they are normal. We went to a private hospital in the south; they did an MRI for the brain and reached the diagnosed of paralysis, and then we came here. My child was recently diagnosed as cerebral palsy. The physician met us — myself and his father — and explained to us that our sons have mild cerebral palsy, and by the exercise they will be able to walk.

M4: I did not notice any abnormality. One of my relatives visited me and she saw Rg and asked why she was not moving like the other kids. At that time, Rg was four months of age. I took her to the hospital in the north region, and doctors said she is normal. Then we went to Jordan and the doctors diagnosed her as cerebral palsy. And he said the reason was because of a difficult birth. The doctor supposed a delivery by C-section.

M5: At the age of four months, we noticed that Mo was not moving and he was not making any sounds. We went to the hospital at the beginning and they said he was normal, and then later on they diagnosed him as cerebral palsy.

M6: My son is a premature baby and he stayed one month in the neonatal intensive care unit. Before discharge they told me that he has brain atrophy and he might not walk.

Sana: Do you feel the same about the term now as when you first received the diagnosis?

M1: Ab is my first child. I was shocked when they told that he has a problem. By the time I accepted the problem, Ab was 11 months of age at the diagnosis. I said to myself, “oho, my son will be disabled and will not move”. Thank God now — with the physiotherapy and Botox injection, he improved. I treated him in different centres and hospitals. After his father’s death, I approached the prince to get acceptance to be admitted to a
rehabilitation centre. He received rehabilitation there and then he was discharged. After that he deteriorated. I also tried a baclofen pump, but I was not satisfied with it. I went for traditional treatment and they advised me to remove the pump. His doctor refused to take it out and I asked to stop the medication under my responsibility. The physicians insisted that my child had cerebral palsy. I have noticed improvement with the traditional treatment; Ab can extend his arms now.

M2: I felt sorry at the beginning, but thank God her case is very mild.

M3: At the beginning when I read his report, I was horrified. I said, “No, my children are ok”, because they wrote cerebral palsy with mental retardation quadriplegia delayed in speech. I asked the doctor why he wrote cerebral palsy in the report, and he said that they had the mild type of cerebral palsy. I am finding it very difficult.

M4: I found it very hard, and it’s very difficult for me to accept. I was shocked and I felt the world was very dark, but by the time I was used to the situation, I saw children had the same problem.

M5: I was surprised and shocked. I did not expect that my child would be disabled, and then I started to treat him. I started the physiotherapy session and then I got used to it. First we did not have any information about cerebral palsy; it was a very new term to us.

M6: At the beginning I cried a lot. But by that time, I accepted his problem.

Sana: After diagnosis, was any support provided for you? What was the nature of this support?

M1: Yes, his father was very supportive. When he heard that Ab had a problem, he went to a different hospital and centre for the treatment. He used to say that he wanted his son to be normal to be able to walk like other kids, and like his brothers. His father died nine years ago. But he was very supportive.

M2: Her father died when she was three years of age, but he was supportive. He used to go with her to the hospital for the appointment.
M3: My husband and my other children were very supportive; they helped me with taking care of them. Also, my sisters are helping me. Since we started the rehabilitation last month till now, he has been with us and he has not left us — and he applied for vacation to be with us.

M4: My husband is very supportive. Since her diagnosis, he has not left her. He took her to Jordan for treatment and he went with her to Czech Republic for rehabilitation.

M5: My husband and Mo’s brothers were very supportive; they help and they take care of him.

M6: Yes, my husband is supporting me; he treated him in different hospitals, and he also took him for traditional treatment. He employed a private physiotherapist for Az. At the beginning my mother and aunts told me to admit him in disabled centres and to leave him till he became dependent, but I refused.

Sana: How do you feel when people describe your child as having cerebral palsy?

M1: To tell you the truth, I don’t accept the society attitude toward my son. All of the people say, “oho, he is not walking”, and they look at him and to his wheelchair like a person coming from another planet. They said that he is handicapped and asked why he is like this... ok, why do they say that? Any one of us might have a car accident and become handicapped. This is from God, and it is out of my hand to have a child who is not walking.

M4: People in Saudi Arabia see the cerebral palsy child different than others. They treat her as aliens, especially when she gets out in the shopping mall or at the school. I don’t like the Saudi’s attitude toward the handicapped. We went to Jordan and to Kuwait, but I did not see this attitude — it is only in Saudi Arabia. The women in our society blame the mother if she gets a child with cerebral palsy. On my second birth, all of the women were waiting to see if I got a normal or handicapped child.
The school is another story: when I decided to enrol Rg in school, I went to the school director, I explained to her my daughter’s situation, and I told her that I am worried about the girls’ attitude toward my daughter. She said that I shouldn’t worry and that she will find a solution. Then she met the girls and told them that they may have a handicapped child join them soon. ("Please deal with her like other girls — don’t look to her with strangeness.") The first day in the school was not easy for me and for Rg as well. Rg studies in the normal mainstream school. I always say to Rg, “Don’t bother with what the people say or look at”. I tried to build the confidence for herself.

M2: I don’t like any one to say she is not walking well or to be sarcastic to her. I don’t like any one to hurt her feelings.

M3: My sons are very small and I did not take them out a lot, but I don’t like anyone to look at them strangely.

M5: People look at him with pity and compassion: “Oho, he is a poor boy.” They don’t understand his condition and his problem.

M6: In our society it is very shameful to have a handicapped child. If you have a handicapped child, then it is shameful to take him out with you — you have to hide him from the people. Society blames the mother.

Sana: I really appreciate your willingness to express your feelings about that.

Would anyone like to add more comments? Or do you have anything else that you want to share with me?

M1: Thank you very much for having this chance to talk about our feelings and experience. I encourage you to continue doing this meeting, even when you are done with your research. I also would like to recommend intensive physiotherapy. Therapists and doctors say that parents play a role, I agree, but we are doing our best at home. Here in the hospital you have equipment, and therapists know better than us. They know how to deal with the case better than us.

M4: Thank you. This is the first time for me to talk with other mothers. I find it very helpful to share the experience and the feelings, and I do agree with Um Ad that it is difficult to do PT at home — we have other duties.
Appendix 19: Children’s Interview Transcript

Interview 2

AN is a 17-year-old girl with spastic diplegia
Her GMFCS is III
She has a private PT who comes to her house three times per week
Her mother is a school teacher
During the recruitment, AN’s mother told me that she told AN everything about her condition and that she built her confidence and acceptance
She also said that she always told AN to remember what Allah (God) almighty has said: “If you give thanks, I will give you more.”

She came to the interview with her mother. At the beginning, AN was not comfortable, when I asked her why she said that she preferred to talk with me alone without the presence of her mother
I asked the mother to wait outside, and the mother was very understanding and she waited outside
AN got relaxed and she said she wanted to talk without any restrictions
The interview took about 95 minutes

Sana: Hi, as I told you before, my name is Sana, and I am a physiotherapist who helps children with a disability. I want to thank you for being a part of the study. My research project is called ‘The perception of the term Cerebral Palsy (CP) in Saudi Arabia’.
The reason why I am doing this is because I want to learn more about the meaning of the term “cerebral palsy”.

I also want to know about your everyday life and how you live. I hope that by learning from you, we will be able to develop programmes that are more helpful to you and other children like you to live better — and enjoy life more.

All of your answers will be only between you and the research team. If you ever feel uncomfortable or you don't want to answer any of the questions, you don't have to answer that question and you can stop the interview anytime.

The interview will take about one hour depending on how much you have to say. Would it be okay for you if I audiotaped this interview just in case I miss something?

**AN:** Yes.

**Sana:** If at any time during the interview you would like to turn the tape recorder off, all you have to do is say so. Before we start, do you have any question about the interview?

Ok, dear. Can we start our interview?

**AN:** Yes ... before we start, can I ask you something?

**Sana:** Sure.

**AN:** I don’t want my mother to stay with me.

**Mother:** Ok, I will wait outside.

**Sana:** Ok, can we start now?

**AN:** Yes.

**Sana:** Would you please tell me how old you are?

**AN:** I am 17 years old.

**Sana:** Do you go to school?

**AN:** Yes, I go to a private school. I am in secondary school grade 2.
Sana: Excellent!

Sana: Can you tell me what your favourite food is?
AN: I don’t have any favourite food. I like all kinds of food.

Sana: What do you like to do in your spare time?
AN: I play with the iPad. I spend my time browsing the Internet.

Sana: What do you browse?
AN: I search for disability.
Sana: Excellent. God bless you.

Sana: Do you know what your diagnosis is?
AN: Yes, a lack of oxygen.
Sana: Who told you this?
AN: My parents told me that I had a lack of oxygen.
Sana: What did they say to you?
AN: My mother said that I had a lack of oxygen, and it happened during delivery. My mother had a difficult and long delivery. I did not get out easily, then doctors decided to do a C-section. When I got out, the doctors told my mother that I had difficulty in breathing and this might affect my body.

Sana: Did you stay in the intensive care unit?
AN: Mother said I stayed for 2 months.

Sana: Ok, dear, do you know what the meaning is of “lack of oxygen”?
AN: Yes, I know. During delivery my breathing stopped and the oxygen did not reach my brain and this affected my body.

Sana: Ok, dear, did you hear about the term CP before?
AN: Yes, I heard.

Sana: Ok, from your opinion and your understanding of the term “CP”, can you tell me what it means to you?
**AN:** I believe cerebral palsy is a disorder that affects the body. The person with CP becomes disabled, and his mind will be affected. The body becomes small and will be bedridden forever, and he may understand very little.

**Sana:** Do you think your condition is CP?

**AN:** No, I don’t think. I have a lack of oxygen.

**Sana:** You said that you have a lack of oxygen. Do you think that the brain controls movement?

**AN:** Yes, I know the brain is responsible for the movement.

**Sana:** Tell me why you think that you don’t have CP?

**AN:** Because no one told me that I had CP.

I feel there is a problem in my head, but I don’t know what is wrong with my head. Nobody told me. I want to know what is wrong with my head. No one explained to me what was wrong with my head.

**Sana:** Ok, dear, what did the doctor tell you?

**AN:** Doctors always say I should go to physical therapy and do exercise. They did not explain to me and they did not tell me what were the reasons or causes. Nothing, no one explained to me. I want someone to explain to me my problems.

**Sana:** What do you call your problem when you talk about it, for example, at school? What do you call it?

**AN:** When the girls at school ask me, I say, “from God”. I also mention the lack of oxygen and I cry.

**Sana:** Are you ok? Can we continue?

**AN:** Yes.
**Sana:** Now, I'd like to ask about your experience when you first found out about your disability. How did you feel when you first found that you had a lack of oxygen?

**AN:** I always feel sad. I am very sad. I don’t know what to do. I don’t know how I will overcome my problem and the situation.

**Sana:** Can you explain more?

**AN:** I mean, every day I sit and I cry. I know this is from God, and everything is from God, and I curse myself.

**Sana:** Curse yourself — why do you do that?

**AN:** I want to be like the other girls: sit nicely and cross my legs. Other girls hold each other’s hands. Why am I not like these girls? I always cry. Sometimes I cry in front of my family. Sometimes I cry alone in my room.

**Sana:** Ok, dear, what did your family do when you cried?

**AN:** They can’t answer me ... they say, “this is from God and you should not cry, and this is forbidden. Don’t cry because this is from God”. But I feel relieved after crying.

**Sana:** Please tell me how your problem affected your life.

**AN:** It affects me in getting outside the house. I can’t go to the mall. But thank God my parents take me to the mall. Sometimes they tell me that there are stairs in the mall and I can’t go, and I turn my face and I cry.

**Sana:** Do you cry because you can’t go?

**AN:** Yes, because my mother does not take me with her when she visits our relative or her friends. She says, “AN, there are stairs. I can’t take you with me”.

And I stay alone and I cry.

**Sana:** Do you go to wedding parties?

**AN:** Yes, I go if my mother is willing to take me with her, if she is feeling good. If she does not want, she will give me excuses and she will say that there are stairs and I can’t go.

But she never left me alone in the house. Either she stayed with me or asked anyone from my relatives to stay with me.

**Sana:** Do you have brothers and sisters?

**AN:** Yes. I have three brothers. I am the youngest.

**Sana:** Are they good with you? Tell me how they treat you.
AN: They are very good, thank God. They treat me like their daughter, not their sister. They help me a lot, and they love me a lot. They buy me many things and they never ask me to pay them back. They buy from their own money and then they return my money. Even if I ask them to take the money back, they refuse and say, “keep it — you may need it later”.

Sana: How about your father? How did he treat you differently?
AN: He always helps me when I go to the toilet. He helps me to wear my shoes. Yes, my mother helps me and dresses me, but my father helps me a lot. Also, he cares about me a lot. If I want to get in the car, he helps me. If I want to wash for prayer, he helps me and he pours the water for me. In the toilet he helps me take my pants off and he always says, “I will not see you”, and he turns his head to the other side.

AN: Thank God my father is very good with me, especially during journeys.
Sana: Ohoo! Do you go for journeys?
AN: Yes, thank God.
Sana: Where do you go?
AN: I went to Damam and Yanbou and I also travelled to Germany.
Sana: Why did you go to Germany?
AN: For physiotherapy.
AN: Physiotherapy there is different than here. I had continuous PT sessions there.
Sana: When did you go?
AN: Three years ago.
Sana: Did you improve?
AN: Yes, I improved a lot. I was not able to stand. Then they made me stand and walk alone, but now I am getting worse and weak.
Sana: Can you explain how?
AN: I stopped standing and walking alone. I need help.

Sana: Tell me about your typical day.
AN: I wake up in the morning. Then I dress myself and go to school. After school, I sleep till 4 p.m. On Saturday, Sunday, and Monday, I have a physiotherapy session for one hour. I have physiotherapy three times per week. Then I play with the iPhone and iPad till I go to sleep.
Sana: What do you do?
AN: I search the Internet and play games.
Sana: What are the biggest difficulties that you face during the day?

AN: I have a problem when I communicate with others. People don’t understand me well and it makes me very upset.

Sana: Why do you feel upset?

AN: I am a very socialised person and I like to get with others. And I like people, but I can’t pronounce words correctly and they don’t understand me.

Sana: Does this make you upset?

AN: Yes, a little, but I don’t cry. I can manage. I say to myself, “whether they understand me or not, I will not bother myself”.

Sana: How about dressing?

AN: Before surgery I used to dress myself without any help, but after surgery I couldn’t. I need someone to help me because I can’t turn my leg.

Sana: Ok, who helps you?

AN: My mother.

When did you have the surgery and what type of surgery did you have?

AN: 6 months ago. I had surgery to correct my walking. I used to have walk in-toeing.

Sana: How about eating and walking?

AN: I have no problems.

I don’t have any problems. I can walk with a walker. I used the wheelchair very seldom when I go out and for long distances.

Sana: How do you manage bathing and toileting?

AN: I go to the toilet myself. My mother helps me bathe. Now she is trying to make me independent in bathing, but I don’t think I can.

Sana: How do you move at home?

AN: With the k-walker.

Sana: Do you have stairs at home?

AN: Yes, 22 steps.
**Sana:** How do you manage going up and down stairs?

**AN:** I hold the rail and I go up and down.

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**Sana:** How about the school — do you use a walker or wheelchair?

**AN:** I use the K-walker and I hang my school bag on the walker.

**Sana:** Tell me about your classroom location. Where is your classroom?

**AN:** It is on the ground floor. There is one small step, but I can manage it. I can get in and out of the car, but I need someone to lift my legs up when I sit in the car.

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**Sana:** What do you do during the break at school? Do you go outside to the schoolyard or do you stay in your classroom?

**AN:** I don’t go out because I don’t like to eat at school.

**Sana:** Why?

**AN:** Because the food will spill out my mouth and I feel embarrassed in front of the girls. If I eat chocolate, then my face will be dirty. I eat only at home.

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**Sana:** Tell me how you get along with others. Do you have friends?

**AN:** Unfortunately, this year I didn’t make any friends. I don’t have any friends from my class.

**Sana:** Can you tell me why you don’t have any friends?

**AN:** I don’t like their way and their lifestyle. They talk differently than me. They talk and chat about singers and the TV shows. I don’t like this kind of chatting. If I talk with them about different topics, they don’t listen to me.

But this does not mean I am not a social person. I like to get along with others. I say “hi” to the girls at the school and I pass by to the other class and say “hi” to the girls. I ask them about their exams, but I don’t have a special friend.

But before, I used to have friends when I was in the primary school. Now the girls are very different. I can’t get along with them.
**Sana:** Why?

**AN:** Because I am not interested in their chatting topics.

**Sana:** Can you tell me how your classmates and the girls at school treat you?

**AN:** Nothing special. They avoid embarrassing me and they don’t say bad words to me.

**Sana:** How about the schoolteachers?

**AN:** Same thing. They treat me like other girls in the class. But during exams they help me understand the questions.

**Sana:** Do you feel embarrassed because of your disability?

**AN:** I used to, but not anymore.

**Sana:** Why?

**AN:** Because the normal people gaze, stare, and look at me. When people see me with a walker, they stare. I am the only person using a walker. Now I don’t care. If they stare, I stare back.

**Sana:** Why?

**AN:** Because I get used to my disability and I am trying to accept it.

**Sana:** Do you have any girls with a disability at your school?

**AN:** Yes, only one.

**Sana:** Is she in your class?

**AN:** No, she is in the elementary class.

**Sana:** Do you see yourself as different from other girls at the school?

**AN:** I don’t feel a very big difference. The girls can sit with crossed legs. They are slim. Their attitude makes me very upset.

**Sana:** Can you tell me more?

They sit with crossed legs and they hold the biscuits softly. I see myself as fat and puffy. I have very big hands ... I can’t sit with crossed legs. I don’t mean in front of men. I want my appearance to be nice in front of the other girls. My appearance and my looks make me very upset.

They all have friends except me.

**Sana:** Ok, dear. Are you ok? Can we continue?
**AN:** Yes.

**AN:** I see my walking as very different than other girls.

**Sana:** Do you think you feel different because you are using a walker?

**AN:** No, not because of the walker. I don’t feel upset because of the walker. I feel upset because of the girls’ attitude and behaviour.

**Sana:** Can you tell me why you feel upset?

**AN:** I feel upset when I see them hold and touch hands, and I don’t. Even if I try to hold one, she refuses and she will say, “I am afraid that you will fall down and I don’t want to be responsible”. Yes, this makes me embarrassed.

**Sana:** What do you fear most about your disability?

**AN:** I am afraid of falling down.

**Sana:** Do you think you will be able to walk alone in the future?

**AN:** If God wills. If the God wills, I will be, but I don’t think I will be able to walk alone.

**Sana:** Why?

**AN:** Because the PT here is the same, and nothing is new. I am not improving. In Germany the PT was continuous.

**Sana:** Do you think that if you have a chance to go to Germany again, you will be able to walk?

**AN:** Yes, because when I went to Germany, I was not able to walk and then I started walking alone. I remember the doctor was holding my hand, then he released his hand and then I walked.

**Sana:** What is your expectation about your motor level in the future?

**AN:** I see myself walking with a walker; I don’t think I will be able to walk alone without a walker. However, if God wills, I will be able to walk alone.

**Sana:** What do you want to be when you grow up?

**AN:** I want to be a special education teacher.
**Sana:** Why?

**AN:** I like to deal with the disabled. I feel they are better than the normal people.

**Sana:** Can you explain more about how they are different?

**AN:** They smile all the time. I have noticed this with the disabled girl at my school. She always smiles and offers help to me. I know she cannot help me, but she offers help. She always says “hi” to me. Normal people don't care. They don’t say “hi” or “hello”. I have found the therapists’ attitude with me and how they deal with me to be very good. I have learned from them how to deal with the disabled.

**Sana:** Can you tell me how?

**AN:** Here the therapists are very good with the disabled. They respect the disabled and they don't underestimate their level and function. They give hope.

**Sana:** Do you think girls at school underestimate you?

**AN:** Yes.

**Sana:** How?

**AN:** Because they cannot be my friend.

**Sana:** What do you hope and dream for?

**AN:** I wish I was slim and had nice and stylish hair. I want to sit with crossed legs. I want nice and soft hands. I don’t want my hands; my hands are very big. I want to have friends and to get out with them and to hold their hands. I don’t want to hold my friends’ hand strongly. I want to touch their hands and their fingers. However, my family told me that my wishes were very silly.

**Sana:** Why did they say that?

**AN:** They always say to me to thank God. Maybe they don’t want to embarrass me. Maybe they want me to think wider and more mature. They say, “we all don't have friends, so don't feel sad because you don't have friends”.

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**Sana:** At home, do you have a close relation with your family?

**AN:** Yes, very close and all are friends with me.

**Sana:** Do you play any kind of sport?

**AN:** No, I can’t.

**Sana:** I really appreciate your willingness to express your feelings. You are helping me understand—and that's exactly why I wanted to interview you.

Do you have anything else that you want to share with me?

**AN:** I want to go abroad. I want to have treatment abroad. I want to be like other girls. This is what I want. I want to be like other girls.

Thank you for giving me the chance to talk. It was my wish to talk with someone. Usually, when I go to physiotherapy or a doctor’s appointment, my parents stay with me, and they answer instead of me.

Thank you for giving me this chance. I was waiting for this a long time ago. Thank you because I never had this chance before.

**Sana:** That's the whole interview. We're done. Thanks for participating. I would like to give you something to show that I appreciate you sharing with me your experience and your time. Thank you.
Appendix 20: The Children

**Child ST**

ST is a 16 year old boy and the eldest of three sisters and one brother, who lives with his family in the western region of Saudi Arabia. He was born with Spastic quadriplegia and has dysarthria but speaks well and with enthusiasm. He uses a powered wheelchair for mobility. He was at GMFCS level IV. I met his father 10 days prior to interviewing him to discuss with him the study. His father described his son as a responsible boy, who attends private mainstream school, and was in the third grade of the intermediate school. His Father is a very religious man. I did not meet ST's mother because she stayed at home with her other children.

ST was the first child who interviewed, we met in the small conference room located at physiotherapy department. During the interview he used his hands a lot, and pointed to his head when we talked about CP term. At the beginning of the interview I had difficulty to understand him because of his dysarthria, and I asked him to repeat what he had said to me. When he calmed down his speech became clearer to understand.

**Child AN**

AN is a 17 year old girl and the youngest of three brothers. She lives with her family in Riyadh. She was born with spastic diplegia, she was at GMFCS level III. Three weeks prior to interview, I met with her mother to talk about the study and she told me that AN was aware of her condition and she said that she helped her to build her confidence in order to help her to accept her disability. She also said that she always told AN to remember what Allah (God) almighty has said “If you give thanks, I will give you more”.

Her mother is a very religious person, and is a school teacher. She was very keen to bring her to physiotherapy clinic regularly and also hired a private
Physiotherapist, who visited her house three times per week. AN attends a private mainstream school, and was in the first grade of the secondary school.

AN came to the interview with her mother, using a walker for locomotion. She wore Abaya (traditional Saudi Dress) and covered her face. We met in the small conference room located at physical therapy department. At the beginning of the interview AN was not comfortable, and when I asked her why, she said that she preferred to talk with me alone, without the presence of her mother. I asked her mother to wait outside to give her the space to talk freely about her experience and feelings, her mother was very understanding and waited outside.

When her mother left the room, AN took a deep breath and said "I want to talk without any restrictions". She then relieved in the interview, and was chatty and eager to answer all the questions.

**Child NI**

NI is a nine year old boy and the eldest of three brothers, who lives with his family in Riyadh. His father is a businessman and his mother is a housewife. He was born with spastic diplegia and was classified at GMFCS level IV. He attends a governmental mainstream school, and was just enrolled into primary school this year.

NI came to the interview with his maid (she stayed outside), whilst his father dropped him and left to go to his work. His mother did not come because she was busy with the other kids. I met him in the small pediatric treatment room following his physiotherapy session, he was standing with the standing frame (he chose to be interviewed while standing). He was a happy boy smiling all the time, had pleasant expression the majority of the interview, however he was not comfortable when I asked him questions about his disability.
**Child MD**

MD is a ten year old boy lives with his family in Najran the southern region of Saudi Arabia. His family was quite big consisting of 3 brothers and 2 sisters. MD was born with spastic diplegia. He was classified at GMFCS level III. He goes to the government mainstream school, and was in the second grade of the primary school at the time of the interview. His father was a religious man who came from Najran to see the doctor and to attend the interview. His father was a very understanding person. He left the room and stayed outside during the interview and said "better to be with MD alone to feel free." MD was happy and very cooperative, polite boy, with a pleasant personality. Despite never having met before, he spoke easily and confidently with me.

**Child HN**

HN is a 12 year old girl, the youngest of eight brothers and sisters, who lives with her family in Riyadh, she was born with a very mild spastic diplegia. She was classified at GMFCS level I. She attended a government mainstream school, and was in the fifth grade of the primary school. She came to the interview with her twin sister and her older sister, and asked my permission to allow them to attend the interview with her. We met in the small conference room located at physiotherapy department. She was very cooperative, smiling, and was energetic and very talkative throughout the interview.

**Child AB**

AB is a 17 year old boy with spastic hemiparesis, who lives in Riyadh with his family. He was classified at GMFCS level I. He attended mainstream school, and had many friends. Both mother and father are educated. We met in the small conference room located at physiotherapy department. We had never met before, and began the interview speaking freely, fluently and with enthusiasm. He especially enjoyed talking about his friends and
schools. He was very confident when he talked about his life, understood his disability and did not feel ashamed about it.

**Child DH**

DH is a five year old boy, the eldest of one sister and the youngest participant. He lives in the north of Saudi Arabia in a small town. DH was born with spastic quadriplegia and was at GMFCS level III. He attended the rehabilitation centre as an inpatient in Riyadh for intensive physiotherapy. I met his mother prior to interview she said that “he is a cooperative and shy boy and he rarely gets out of the house”. DH was not attending school. We met in the paediatric gym after his physiotherapy session which had some toys and small table at which we sat. DH, invited his nanny to attend the interview with me. His mother did not attend, however she came at the end of the interview. I used talking mats with him to facilitate the communication and make the interview simple, understandable and appropriate to his age.

Throughout the interview he kept moving his head, and his body. He stood several times, played with his eyes and hair. In the middle of the interview he asked me to stop and he played with puzzle, then he ask to resume the interview.

**Child MH**

MH is a 13 year old boy and the youngest of many brothers and sisters. He used to live with his father in a small town, very recently he moved to Riyadh to live with his sisters. His father is an old man. He did not mention his mother at all. He has brothers and sisters but he did not tell me how many.

MH was born with spastic diplegia, and was classified at GMFCS level IV. He never went to school. He never had chance to go to physiotherapy clinic before. He came for the interview with his 2 sisters. During the interview, I have found that MH denied his disability and he perceived himself as an
ordinary child, and he avoided talking about his disabilities and difficulties as well. He was very quiet and did not expand upon his answers. I did my best to get the maximum out of him.

**Child MA**

MA is an eight year old girl and the youngest of two brother and sister. She came from Jeddah (western region of Saudi Arabia) for her physiotherapy appointment and for the interview. Her father is very educated and understands her situation very well. I did not meet her mother, who stayed in Jeddah with her other children. MA was born with spastic diplegia, and was classified at GMFCS level IV. Her speech and perceptual functioning was impaired so I used the talking mats to facilitate the communication with her. She came to the physiotherapy clinic in a wheelchair and was able to propel her wheelchair by herself. She used her hands a lot and pointed to her legs many times. MA attends a disabled children association school, and was in the first grade.

She told me that her age was 6 years but her father said that it was 8 years. She also told me that she was in grade 2 but her father said that she was in grade 1. She did not know her school name. She kept asking me about her father during the interview, I asked her father to stay with us but he preferred not to attend.
Appendix 21: CP Spidergram
Appendix 22: Peer-reviewed Abstracts (Archives of Disease in Childhood.)

1753 The Perception of the Term Cerebral Palsy (CP) in Saudi Arabia
S Madi, A Mandy and T Pountney
Arch Dis Child 2012 97: A495-A496
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Appendix 23: Poster Presentation: The Posture & Mobility Group

National training event

Aims and Objectives
The purpose of this qualitative study was to explore the perception of the term CP with Saudi mothers of children with CP, and to explore the implication of the meaning of mothers of children with CP within Saudi Culture.

Background
CP is one of the most common childhood disabilities and makes heavy demands on health, educational, and social services as well as on families and children. In Saudi Arabia there is limited understanding of CP. The term Cerebral Palsy is recognized by most health and social service professionals as a physically disabling condition; however this is not the case for the general public nor, more importantly, for mothers of children with CP. Misinterpretation of the term CP in the Arabic language clearly exists. In addition there is a lack of research describing people's perception of the CP term in Saudi Arabia.

Methods
Critical ethnography was adopted as the methodological approach; data were collected through focus groups, follow up individual interviews, field notes and participant observation. Carper's five-stage method of critical ethnography provided a theoretical framework for data analysis.

Findings
Three themes emerged from the data: (1) Religious and cultural beliefs, (2) Aspiration and Optimising the child’s future, and (3) Community Stigmatisations.

"I believe what happened to my son was a strong evil eye that hit his health. I felt it one day when I had a large gathering in my house and one of the ladies without saying God protect you from evil, "she said you have a pretty child", M6

A unique finding of the study was the influence of Islam in all of the mothers’ focus group themes. Although most of mothers use the medical terminology and explanation for the cause of CP, they also constantly highlighted various religious and socio-cultural causal agents. The mothers also expressed a deep trust in God (God’s will), and relied on God for their child’s cure and better health outcome using these beliefs to cope with their children’s circumstances. Another important issue related to this theme is that mothers’ religious and socio-cultural beliefs hinder the process of treatment, and tend to discourage them to seek assistance outside of rehabilitation services, such as taking advice from traditional healers. The findings of this study clearly indicate that mothers were perceived as major source of support by their husbands, mothers and sisters. However, they believe that having a child with CP introduced great changes in their life style and stopped social events with their relatives and friends not only because of the child burden on the mother but also because of not accepting the child in society.

Discussion
This study has provided preliminary data on the perception of Saudi mothers who have a child with CP. It presented the voice of mothers of children with CP about their perception, experiences, their own processes of adaptation and coping within the Saudi cultural context. The findings revealed that the dominant aspect shared across the data and the themes were the issues of culture, religion, and traditions related to disability. This study found a strong link between perception of disability and religious and cultural beliefs suggesting that the concept of disability is framed from a spiritual perspective, not according to western disability models frameworks.

Moreover, the study explored the community and society attitude towards the child with disability and its consequences which include the stigmatisation and exclusion from the society. It also explored the impact of these negative attitudes on the mother's perception, experience and expectations, therefore in order to enhance better understanding, and integration into community, the study can help to recommend a process of mainstreaming Saudi children with CP and their families into the community, as the mothers noted that increased understanding of disability in the greater community would facilitate integration of their children.

These findings can also provide physiotherapist and health professionals with insight into the experiences those mothers in Saudi face. Outside Saudi, the experiences and cultural beliefs may be useful to health professionals who treat Saudi children who have seek medical advice abroad, as well as populations with strong similar religious beliefs.

Summary
This research report the study conducted in Saudi Arabia, it has allowed mothers of children with CP to express their belief about the term CP. The data yielded information regarding mothers’ beliefs surrounding the meaning of the CP term. These ranged from traditional and cultural beliefs to medical explanations, and to frank confusion between the two.