

Maternal Belief system regarding Independence of children with cerebral palsy among Saudi mothers

Rayya AlKhudair BSc, MSc.

Thesis submitted to the University of Nottingham for

The degree of Doctor of Philosophy

December 2018

Abstract

Background: Cerebral palsy is a non-progressive condition that causes neurological disorders, and is one of the main causes of child disability in Saudi Arabia. Different treatment methods are proposed as part of the rehabilitation plans for children with cerebral palsy. These are usually designed to improve the child's functional skills, so as to develop their independence, as a major goal. Parents have a major role in their children's rehabilitation programmes, therefore their understanding of their child's expected abilities and outcomes is essential. In order to understand the parent's analysis of their child's development it may be helpful to explore their beliefs. An overview of the existing literature showed that a number of studies investigated parental beliefs regarding the causes and meanings of their children's disabilities, the unique skills of the professionals, the impact of religion and also their behaviour toward independence. Whilst some studies addressed some parental behaviour towards some aspects of independence, the current study is the first to explore parental beliefs focusing on different aspects of the independence of children with cerebral palsy.

Purpose of the study: the current study aimed to explore maternal belief systems regarding the independence of children with mild and moderate cerebral palsy among Saudi mothers.

Methods: the study adopted an interpretive descriptive strategy, using two rounds of qualitative semi-structured interviews. The interviews took place in two rehabilitation centres in the eastern province of Saudi Arabia. Saudi mothers of children with mild and moderate cerebral palsy aged from 6.5 to 14 were recruited. Iterative interpretive thematic analysis was used to analyse the obtained data.

Findings: Nineteen Saudi mothers of children with mild or moderate cerebral palsy were recruited. The study reveals maternal religious and cultural beliefs related to their children's development to achieve independent. It also provides knowledge about the mothers' beliefs regarding their children's potential to be independent, showing the maternal understanding of independence and their expectation of their children's abilities to be independent. It also revealed the maternal beliefs regarding the motivations, precautions and techniques of child training to be independent, highlighting at the same time those beliefs regarding the family members' role in the training process. The current findings also proposed factors that might contribute to constructing the mothers' beliefs, factors related to the mothers, the children, and external factors.

Conclusion: the study found that the mothers' understanding of independence is not unique and that they provided different

understandings and prioritizations of independence. It was also found that maternal beliefs regarding independence can be identified through an understanding of their beliefs regarding the potential and training to be independent. It was also found that maternal beliefs were informed by religious and cultural beliefs, and influenced by multiple factors. Therefore, capturing the relation of different maternal beliefs provided more understanding of maternal belief systems regarding the independence of children with cerebral palsy.

Acknowledgment

First I want to thank all of the mothers who participated in this study and allowed me to share their stories, feelings and experiences. Listening to them was for me one of the greatest life learning experiences.

Deep thanks and gratitude to my supervisors Dr. Jo Lymn, Dr Pippa Hemingway, and Dr Claire Diver. Thank you for all of the support and encouragement you gave in this journey; I appreciate your guidance in all of the stages of my PhD. You helped me to broaden my thinking and challenge myself.

My dad: thank you for your incredible physical, emotional and moral support; it has played a major part in my study journey. Your inspiration taught me the passion of seeking knowledge. My mother: thank you for the lifetime support and for the endless sacrifices you made for the sake of my education. Deep thanks to my little family: my husband Asem, my little ones Lama, Sarah, Reema, and Abdulrahman, thank you for your support, your little eyes were a great source of motivation. My sisters and brothers, Lama, May, Maha, Ali, Abdullah and Sarah thank you for always being there when needed and for your endless support.

To all my friends and cousins, thank you for your continual support. I want also to specially thank my friend Dr Maha Atout for her valued support during the different stages of my study. Finally, I am indebted to my country, Saudi Arabia, that provided me with the chance to have this experience by sponsoring my doctoral studies.

Table of Contents

Abstract ..... **ii**

Acknowledgment ..... **v**

List of Tables ..... **xii**

List of figures ..... **xiv**

Chapter 1: Introduction and Background **16**

1.1 Relevance of the proposed study 16

1.1 Cerebral palsy 17

1.1.1 What is cerebral palsy? *17*

1.1.2 Types of cerebral palsy *18*

1.1.3 Prevalence and incidence of cerebral palsy in Saudi Arabia. *21*

1.1.4 Cerebral palsy causes and risk factors *23*

1.1.5 Management of cerebral palsy *25*

1.2 Child independence 27

1.2.1 Development of independence in able-bodied children *28*

1.2.2 Development of independence of child with cerebral palsy ... *32*

1.3 Beliefs 34

1.3.1 What is a 'belief system'? *35*

1.3.2 Parental belief systems *37*

1.3.3 Parental child rearing beliefs and child independence *40*

1.4 Overview of Saudi Arabia 42

1.4.1 The role of religion and culture in Saudi Arabia *46*

1.4.2 The family in Saudi Society *48*

1.5 Conclusion 50

2 Chapter 2: Literature Review 51

2.1 Aim of the review 51

2.2 Search strategy 51

2.3 Literature review 65

2.3.1 Understanding of disability 65

2.3.2 Impact of culture and religion 69

2.3.3 Unique skills of the professional 72

2.3.4 Behaviour toward independence 74

2.4 Conclusion 76

2.5 Identification of research gaps 77

2.6 Research question 78

2.7 Aim of the study 79

3 Chapter 3: Methodology and Research Methods 80

3.1 Methodology 80

3.1.1 Critical realism: ontology and epistemology 80

3.1.2 Study design: interpretive description strategy 86

3.2 The Study Methods 91

3.2.1 Study sites 91

3.2.2 Sampling strategy 93

3.2.3 Sample selection 96

3.2.4 Sample size 96

3.2.5 Sample recruitment 98

3.2.6 Data collection 99

3.2.7 Data Analysis 112

3.2.8 Ethical considerations 124

3.3 Conclusion 128

4 Chapter 4. Findings: Study participants 129

4.1 Study participants 129

4.2 Maternal beliefs regarding the independence of children with cerebral palsy 131

4.3 Maternal religious and cultural beliefs and their relationship with other maternal beliefs 133

5 Chapter 5. Findings: Maternal religious and cultural beliefs.. 138

5.1 Rely on God 140

5.2 Islamic beliefs 153

5.3 Cultural beliefs 168

5.4 Conclusion 178

6 Chapter 6. Findings: Maternal beliefs in the child's potential for independence 180

6.1 Mothers' understanding of independence 182

6.1.1 Cognitive development 182

6.1.2 Personality development 190

6.1.3 Physical development 197

6.1.4 Beliefs in the priority of independence 205

6.2 Beliefs in their child's functional abilities 212

6.2.1 Expectations regarding child abilities 213

6.2.2 Supporting child's ability 223

6.3 Conclusion 228

7 Chapter 7. Findings: Maternal beliefs in training their child towards independence 231

7.1 Mothers' involvement in their children's training 232

7.1.1 Training motivation: separation and burden beliefs 233

7.1.2 Training avoidance 238

7.1.3 Mothers' training education 244

7.1.4 Creating techniques 247

7.2 Roles of family members 257

7.2.1 Beliefs about fathers' role 257

7.2.2 Beliefs about the role of siblings 268

7.3 Conclusion 273

8 Chapter 8. Findings: Factors that Influenced Belief Development 275

8.1 Factors related to the mothers 276

8.1.1 Mothers' feelings 277

8.1.2 Mothers' physical health 284

8.1.3 Mothers' behaviour 286

8.2 Factors related to the children 296

8.2.1 Children's characteristics 296

8.2.2 The impact of children's improvement 302

8.2.3 Children's health status 305

8.2.4 Children's speech status 309

8.3 External factors 312

8.3.1 Extended family 312

8.3.2 Surrounding society 315

8.4 Conclusion 317

9 Chapter 9: Researcher Reflexivity 321

9.1 Reflexivity 321
9.2 Pre-research stage 322
9.3 Theoretical perspective 324
9.4 Pre-data collection 327
9.5 Data collection and analysis 330
9.6 Conclusion: 339

Chapter 10: Discussion and conclusion 341

10.1 Introduction 341
10.2 The socio-ecological model 342
10.2.1 Applying the modified socio-ecological model to discuss the findings 343
10.3 Macrosystem: Maternal religious and cultural beliefs 347
10.3.1 Religion as a coping strategy 347
10.3.2 Gender difference 354
10.4 Exosystem: Factors that influence the development of maternal beliefs 356
10.4.1 Fears of future 356
10.4.2 Mothers' effort and patience 358
10.4.3 Beliefs regarding child responsibilities 359
10.4.4 Role of extended family 360
10.5 Influence of the microsystem 362
10.5.1 maternal understanding of independence 362
10.5.2 Maternal expectations of independence 365
10.5.3 Motives to train 368
10.5.4 Training avoidance 370

10.5.5 Maternal beliefs of the father's role 371

10.5.6 Maternal beliefs about siblings' roles..... 373

10.6 Limitations of the study 374

10.7 Practical implications 376

10.7.1 Implications for clinical practice 376

10.7.2 Further research 378

10.8 Conclusion 380

References 382

Appendices 399

Appendix 1: Ethical approval from PSRC 399

Appendix 2: Participants information sheet 400

Appendix 3: Consent form 406

Appendix 4: Interview guide (first round) 407

Appendix 5: Second Round Interview Guide 408

Appendix 6: Interview guide of pilot interviews 414

Appendix 7: Coding process 415

Coding according to the ladder of engagement 415

Appendix 8: Ethical approval from HSJC 417

List of Tables

Table 1.1.Physiological classification of cerebral palsy 19

Table 1.2. Geographical classification of cerebral palsy 20

Table 1.3. Classification of cerebral palsy according to severity 21

Table 1.4. Variation in birth weights in 412 children from 1984-2003 22

Table 1.5: Regional distribution of chronic neurologic disorders in 45,682 Saudi children 22

Table 1.6. Description of developmental categories 29

Table 1.7. Percentage of each age group among population 44

Table 2.1. Key words using PEO format. 53

Table 2.2. Search inclusion criteria. 54

Table 2.3. Excluded studies. 56

Table 2.4. Summary of the reviewed studies of parental beliefs and perceptions of children with physical disabilities 64

Table 3.1. Stages of the cognitive process 116

Table 3.2. Codes and themes from analysis of the first round interviews. 119

Table 3.3. Example of descriptive codes. 121

Table 3.4 interpretive codes derived from grouping descriptive codes. 122

Table 4.1. Description of the children of participating mothers. 131

Table 8.1. Example of using Gibbs (1998) from my reflexive diary. 336

List of figures

Figure 1.1. Map of Saudi Arabia showing its eastern province. 43

Figure 1.2. Public health service levels 45

Figure 3.1. Illustration of reality according to the three levels of parental beliefs 85

Figure 3.2. Summary of the data collection process. 104

Figure 4.1 Maternal beliefs regarding independence of children with cerebral palsy. 132

Figure 5.1. Maternal beliefs, highlighting religious and cultural beliefs 137

Figure 5.2. Maternal religious and cultural beliefs. 138

Figure 6.1. Maternal beliefs, highlighting mothers' 'beliefs in their child's potential for independence'. 179

Figure 6.2. Subthemes of the theme 'beliefs in their child's potential for independence'. 180

Figure 7.1. The 'Beliefs in their child's training toward independence' theme and its relation to other themes. 230

Figure 7.2. Subthemes of 'maternal beliefs in their child's training toward independence. 231

Figure 8.1. The theme 'factors that influenced belief 274

development' and its relation to other themes.

Figure 8.2. Subthemes of 'factors that influence belief development'. 275

Figure 9.1. Gibbs's Reflective Cycle. (Gibbs, 1998) 334

Figure 10.1. Socio-ecological model 341

Figure 10.2. Modified socio-ecological model representing mothers' beliefs about their children's independence. 342

Chapter 1: Introduction and Background

This chapter will explore the background to the main concepts of the current study, starting with an explanation of cerebral palsy; its causes, types, management, epidemiology and aetiology in Saudi Arabia. Clarification will be provided on the subject of child independence and how it applies to children with and without cerebral palsy. The chapter will include an overview of Saudi Arabia's religion and culture, and the various roles of family members in Saudi society will be examined. It will finish with an explanation of my research position as a physical therapist working with children in Saudi Arabia.

1.1 Relevance of the proposed study

Cerebral palsy is a non-progressive disorder that is commonly associated with neurological disorders, and is a common cause of disability in Saudi Arabia (Al-Sulaiman, 1997). Improving functional skills is a major goal of rehabilitation programmes designed for children with cerebral palsy (Singhi, 2004, Minciu, 2011). A way to achieve functional skills for children with cerebral palsy is to offer them a chance to be independent within their abilities. Therefore, parents' understanding of their children's abilities and recognition of the importance of their child's independence in improving functional abilities is essential for progression in rehabilitation programmes. Only a few studies have been conducted that investigate the belief systems of parents of children with cerebral palsy, or focus on independence. The

proposed research aims to identify overall parental beliefs in relation to the independence of children with cerebral palsy, and will look at parental understanding of the concept of the independence of children with cerebral palsy using different research strands that primarily reflect functional activities.

1.1 Cerebral palsy

1.1.1 What is cerebral palsy?

Cerebral means 'concerning the brain' and palsy means paralysis or limited ability to move (Hinchcliffe, 2007). Cerebral palsy has been described as follows:

> "A group of permanent disorders of the development of movement and posture, causing activity limitation, 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, and behaviour, by epilepsy, and by secondary musculoskeletal problems" (Rosenbaum et al., 2007b).

Cerebral palsy is the result of a primary lesion that occurs in the immature brain and produces a motor impairment; the disorder differs according to the site and severity of the impairment, and in the timing of the development of the lesion. Whilst cerebral palsy is permanent it is not unchanging, and functional abilities and quality of life can be

improved (Mutch et al., 1992, Colver et al., 2014, Rokeach, 1968, Rosenbaum, 2003b). Initial clues for diagnosing cerebral palsy are mostly recognised by observation of the slow motor development of a child affecting their capacity to be independent. This is usually combined with abnormality of muscle tone and posture.

Cerebral palsy prevalence ranges from 2.0 to 2.5 per 1,000 live births (National Guideline Alliance UK, 2017) and occurs more frequently in males than females (Johnston and Hagberg, 2007). Severe forms of cerebral palsy are often associated with comorbidities like epilepsy, problems in feeding, bowel mobility, swallowing, and high rates of infection (Colver et al., 2014). Effective management of these morbidities allows children with cerebral palsy to be as active and independent as their condition will allow (Colver et al., 2014, Shaunak and Kelly, 2017). The life expectancy of children with cerebral palsy is similar to other general populations, however severe impairments such as severe scoliosis or nutritional difficulties reduce life expectancy (Colver, 2016, Colver et al., 2014).

1.1.2 Types of cerebral palsy

The way a child with cerebral palsy moves is affected by the extent of the brain damage, as different movements are controlled by specific areas of the brain (Stanton, 2002). Therefore, there are different types of cerebral palsy which can be classified in a number of ways: physiological, geographical and by severity. Physiological classification divides cerebral palsy into spastic, athetoid, choreiform rigid, ataxic, hypotonic, and mixed forms (Table 1).

Major type	Description
Spastic (80%)	• Velocity-dependent increase in muscle tone with passive stretch; • Joint contractures are common.
Athetoid	• Dyskinetic, purposeless movements; • Joint contractures are uncommon; • Dystonia or hypotonia can be associated.
Choreiform	• Continual purposeless movements.
Rigid	• Hypertonicity occurs in the absence of hyperreflexia, spasticity and clonus; • “Cogwheel” or “lead pipe” muscle stiffness.
Ataxic	• Disturbance of coordinated movement, most commonly walking; • Normal head/neck control.
Hypotonic	• Low muscle tone and normal deep tendon reflexes.
Mixed	• Features of more than one type; • No head/neck control.

Table 1.1. Physiological classification of cerebral palsy (Agarwal and Verma, 2012).

Geographical classification of Cerebral palsy includes monoplegia, hemiplegia, paraplegia, diplegia, quadriplegia, double hemiplegia, and total body (Table 1.2).

Major types	Description
Monoplegia	• One extremity involved, usually lower.
Hemiplegia (30%)	• Both extremities on same side involved; • Usually upper extremity involved more than lower extremity.
Paraplegia	• Both lower extremities equally involved.
Diplegia (50%)	• Lower extremities more involved than upper extremities; • Fine-motor/sensory abnormalities in upper extremity.
Quadriplegia	• All extremities involved equally; • Normal head/neck control.
Double hemiplegia	• All extremities involved, upper more than lower.
Total body	• All extremities severely involved; • No head/neck control.

Table 1.2. Geographical classification of cerebral palsy (Agarwal and Verma, 2012).

Cerebral palsy is also classified according to the severity of the motor development – mild, moderate, and severe – and severity is assessed by residual function (Table 1.3

Severity	Description
Mild	Those without significant functional loss, though they are clearly affected and known to be clumsy.
Moderate	Those who have some limitation of normal activities.
Severe	Those who need to be helped in all but the simplest of everyday activities.

Table 1.3. Classification of cerebral palsy according to severity (Balf and Ingram, 1955).

1.1.3 Prevalence and incidence of cerebral palsy in Saudi Arabia

The world prevalence of cerebral palsy is around 1.5 to 3.6 per 1,000 children (Rondero et al., 2005, Cans, 2007, Eunson, 2012, Kelly, 2005). There is a paucity of literature with a focus on cerebral palsy epidemiology in the Middle East, and Saudi Arabia in particular, however a number of studies have investigated the prevalence and incidence of cerebral palsy in specific Saudi populations (Al-Ghamdi et al., 2002, Al-Asmari et al., 2006, Ansari and Akhdar, 1998, Al Salloum et al., 2011a). The earliest study, conducted by Ansari and Akhdar (1998) in a military complex 60 miles west of Riyadh housing over 1,000 families, revealed a prevalence of cerebral palsy of only 1.2 per 1,000 child population, with these children accounting for 10% of the severe disabilities recorded within that population (Ansari and Akhdar, 1998). Al-Asmari et al. (2006) investigated the incidence of cerebral palsy among 99,788 live births in Riyadh Military Hospital and found 412

children with cerebral palsy (0.41%). This study identified a reduction in the incidence percentage in all cerebral palsy types and subcategories during the study duration, from 1984-2003 linked with birth weight (Table1.4)

BW (g)	1984–1987	1988–1991	1992–1995	1996–1999	2000–2003	Total (%)
≤1800	0	2	5	0	2	9 (2.18)
1801–2499	19	19	12	9	0	59 (14.32)
≥2500	77	75	52	42	14	260 (63.11)
Missing	30	19	23	5	7	84 (20.39)
Total	126	115	92	56	23	412
Incidence	30.60%	27.90%	22.30%	13.60%	5.60%	100%

Table 1.4. Variation in birth weights in 412 children from 1984-2003 (Al-Asmari et al., 2006).

The most recent study to investigate the prevalence of neurological disorders among Saudi children was conducted by Al Salloum et al. (2011), who screened 45,682 children over two years (2004-2005) and determined a cerebral palsy prevalence rate of 2.34/1,000. Whilst this corresponded with several prevalence rates worldwide (Rondero et al., 2005, Cans, 2007, Kelly, 2005, Eunson, 2012) it also showed variability across the country with the highest prevalence rate being in the southern province and the lowest being in the eastern province (Table 1.5).

	Central	West	East	North	South	Total
Cerebral palsy	15 (14%)	12 (11.2%)	13 (12%)	24 (22.4%)	43 (40%)	107
Mental retardation	16 (13.3%)	35 (29%)	20 (16.6%)	21 (17.5%)	28 (23.3%)	120
Epilepsy	10 (25%)	14 (35%)	4 (10%)	5 (12.5%)	7 (17.5%)	40
Other disabilities	11 (52%)	2 (9.5%)	0 (0%)	2 (9.5%)	6 (28.5%)	21
Hydrocephalus	4 (28.5%)	2 (14.2%)	0 (0%)	1 (7%)	7 (50%)	14
Neural tube defects	1 (16.6%)	0 (0%)	0 (0%)	3 (50%)	2 (33%)	6
Myopathies	0 (0%)	3 (60%)	1 (20%)	1 (20%)	0 (0%)	5
Total	57 (18%)	68 (21.7%)	38 (12%)	57 (18%)	93 (29.7%)	313

Table 1.5: Regional distribution of chronic neurologic disorders in 45,682 Saudi children (Al Salloum et al., 2011a).

Differences between provinces were attributed to the high consanguinity rate – marriage between relatives – and the minimum levels of obstetric care in remote areas, alongside the shortage of paediatric neurologists in Saudi Arabia (Al Salloum et al., 2011a).

Among previous studies, associated disorders were found in children with cerebral palsy. For example, in a study of the Al Qassim region, 41 children with the condition had speech difficulties (88.3%); 52.2% had urinary incontinence; and 19.8% had seizure disorders (Al-Ghamdi et al., 2002). Epilepsy was found in 25% of children with cerebral palsy (412 children) in the Al-Asmari study; 44.1% were intellectually disabled, and visual impairment was found in 10.7% (Al-Asmari et al., 2006). These associated disorders, especially seizure disorders, urinary incontinence, intellectual disability, and visual impairment must be taken in to account when assessing the functional activities of children with cerebral palsy and expectations of independence.

1.1.4 Cerebral palsy causes and risk factors

The most recent independent risk factors for cerebral palsy, adapted from NICE guidelines, are divided into three categories: antenatal (preterm birth, chorioamnionitis, maternal respiratory tract infection); perinatal (birth weight lower than 1500g, chorioamnionitis, neonatal encephalopathy, neonatal sepsis, maternal respiratory tract infection), and postnatal (meningitis or other infections, head injury).

One of the earliest studies that investigated this was conducted by Taha and Mahdi (1984); it revealed the causes of cerebral palsy to be prenatal (23.5%), perinatal (48.0%) and postnatal (28.0%). Anoxia and

birth trauma accounted for the majority of perinatal causes, postnatally-acquired cerebral palsy resulted from infection, and prenatal cases were due to consanguineous marriages, pulmonary stenosis, or intrauterine infection.

Antenatal risk factors were evident in several studies among Saudi children with cerebral palsy. Low birth weight was the main risk factor in this study, corresponding to Al-Asmari et al.'s 2006 study where low birth weight was found in 68/412 (16.48%); 28 (6.8%) exhibited postnatal aetiology due to infections such as encephalitis, meningitis or severe birth apraxia (Al-Asmari et al., 2006). A study conducted by Al-Sulaiman et al. (2003) to describe the clinical profiles and risk factors of 187 children with cerebral palsy in Alkhobar City demonstrated that low birth weight was the cause in 34% of the cases. In the latest prevalence study conducted by Al Salloum et al. (2011), 17.8% of the sample was documented as having the condition due to hypoxia. De Bildt et al. (2005) showed that hypoxia at birth was the reason for 16% of the cases of cerebral palsy in the Alkhobar city study (De Bildt et al., 2005) and this formed 33% of the Al Qassim region sample (Al-Ghamdi et al., 2002). Preterm delivery was the most significant risk factor in 20% of the sample in the Alkhobar city study (Al-Sulaiman et al., 2003). Kurdi et al. (2004) carried out a study that determined the incidence of multiple pregnancies on preterm labour in Saudi Arabia. The study confirmed that preterm delivery is the most serious complication to arise from multiple pregnancy, which has a prevalence rate in Saudi Arabia of 14/1,000 and 0.72/1,000 respectively (Damignani et al., 2004).

Postnatal risk factors are generally responsible for the lowest percentage of cerebral palsy: 6.8% in Al-Asmari et al. (2006) study, and 5.6% in (Al Salloum et al., 2011a) prevalence study.

1.1.5 Management of cerebral palsy

There is no cure for cerebral palsy, however therapeutic interventions are used to target symptoms such as motor and other impairment (Minciu, 2011). The main goal of treatment for cerebral palsy is not to achieve normalcy or to cure the disease, but to enhance functional abilities and improve capabilities, maintaining levels of health in term of locomotion, social interaction, and development of cognition, and to encourage independence in daily home, school, and community routine activities (Minciu, 2011, Singhi, 2004, Krigger, 2006). There is a growing body of literature on cerebral palsy management that focuses on quality of life and improving the child's social participation by employing new technologies that are directed at both the child and the environment (Colver et al., 2014). Paediatric practice has been found to focus on reducing secondary musculoskeletal deformities more than treating the primary central neurological deficit (Colver et al., 2014).

Choosing the appropriate intervention for a child with cerebral palsy starts with a comprehensive assessment that examines functional abilities, pattern of disorder, severity, pain, age, and discomfort (Colver et al., 2014, Singhi, 2004). According to the National Institute for Health and Care Excellence guidelines (Shaunak and Kelly, 2017), the principles of management include: maximizing the child's functional ability and promoting his or her independence and choice to improve

individual outcomes; working with the child and their family, with continuous reviews of their needs; employing a multidisciplinary team of experts including, for example, paediatricians, physical therapists, and occupational therapists; ensuring optimum communication within the team; monitoring the child for development and clinical comorbidities, and providing the child and caregivers with all necessary information in an appropriate format throughout the rehabilitation journey.

Several treatment methods are proposed to manage each of the problems listed for children with cerebral palsy (Minciu, 2011, Levitt, 2013, Singhi, 2004, Stanton, 2002). From functional therapy to physiotherapy and occupational therapy, it is recommended that most treatments are started early in the first or second year of birth (Bobath, 1967); emphasis is placed on achieving functional skills and independence in self-care such as eating, dressing, and washing (Singhi, 2004, Minciu, 2011). Treatment protocols, such as the neuro-developmental approach (Bobath therapy) have been widely used with children with cerebral palsy to overcome abnormal muscle tone and erase primitive abnormal reflexes (Stanton, 2002, Minciu, 2011). Medical treatments like botulinum toxin injections can also be given to reduce spasticity for more severe cases, in addition to surgical treatment. Splints are commonly used to improve and maintain good joint alignment, as well as walking devices that enable the child to bear weight (Stanton, 2002, Singhi, 2004, Minciu, 2011).

1.2 Child independence

'Independence' is a broad term that evokes several interpretations. Descriptions of independence range from being very general (Turnbull and Turnbull III, 1985), defining it as independent living, to more specific, describing functional independence (Kellegrew, 1998). Some authors also refer to it as the stage when young people separate from their families and start to live independently (English et al., 1994). Freeman (1996) believed that individuals are described as independent when they are able to become self-sufficient and powerful without social support. The concept of independent living was well described by Stiver (1984) as a process of depending on other people to obtain help in managing physically and emotionally with life experiences and tasks when not having enough skills, energy, confidence and time. The concept of 'independent living' is explained here to limit any confusion with functional independence and clarify that it is not the intended area of investigation in the current study.

Child independence has also been described as a reduction in the parent's help while responding to the child's verbal or motor reaction, during the child's experiences, permitting, at the same time, the child to manipulate or explore the surrounding environment (Beller, 1955).

Independence has also been linked with being self-supporting, able to do things for oneself and be self reliant; individuals with a disability who cannot do things for themselves or support themselves and are unable to control their own life, can therefore be seen as dependent (Taylor,

2001). With reference to children with special needs Turnbull and Turnbull III (1985) considered independence to refer to being able to complete physical tasks without assistance, and being able to separate emotionally from the family, parents, or caregivers.

They recommended a 'fix it' model of rehabilitation placing emphasis 'on self-help' skills to minimise functional limitations. The following sections provide a description of independence development among able-bodied children, and children with cerebral palsy.

1.2.1 Development of independence in able-bodied children

Independence is considered to be associated with the ability to be physically fit in order to gain self-support and perform functional tasks (Turnbull and Turnbull III, 1985). Independence is acquired by a child through developing motor and self-care abilities (Tecklin, 2008). Children gain maturation during the transition from infancy to toddlerhood and childhood through *growth* and *development*. Growth refers to the increase in limb size, while development is associated with an increase in control over body movements that will in time give the child independence (Miller et al., 2006). Miller et al. (2006) further argue that what is 'normal development' from the parents' perspective is largely based on family experience, what they have read about parenting, and what advice they receive from physicians. It can be said that a child's development is 'on track' when their skills reach the stage where the potential is there to allow them to participate successfully within their environment. Child developmental skills fall into distinct areas recommended by Raikes (2017) to be appropriate roughly for

children between four and six years. These developmental skills are divided into a number of categories: executive function, socio-emotional development, pre-academic skills, and motor development (Raikes, 2017). The description of these categories is set out in Table 1.6 below.

Developmental category	Description
Executive function	Self regulation, learning skills and academic performance including attention and memory.
Social-emotional development	Includes successful interaction and a positive relationship with peers and adults.
Pre-academic skills	Includes early mathematics and literacy skills.
Motor development	Includes gross and fine motor development.

Table 1.6. Description of developmental categories (Raikes, 2017).

Usually, early motor achievement of the child is linked with the achievement of developmental milestones as measured by scales such as the Bayley Scales of Infant Development and the Denver Developmental Screening Test (Bayley, 1993, Frankenburg and Dodds, 1967).

Independence has been linked with the acquisition of functional skills in evaluations using outcome measures such as the Pediatric Evaluation of Disability Inventory (PEDI) and Functional Independence Measure for children (WeeFIM) (Haley, 1992, Msall et al., 1994). Both measures

focus on three domains of functional skills, *self-care, mobility*, and *social activities*, which reflect aspects of a child's independence. The self-care domain focuses on skills of activity and daily living, such as eating, bathing, grooming, and so forth. The mobility domain focuses on transferring skills and body transport activities, and the social activities domain focuses on social interaction.

It is suggested that a child's motor development can be used to predict the natural progression toward physical independence (Tecklin, 2008). Child motor activities require motor development that is essential for developing movement patterns and skills to perform tasks. Motor development includes neuromuscular maturation, physical growth, and biological maturation, as well as age-related changes in posture and movement (Malina, 2004, Tecklin, 2008). A developmental milestone is usually used to 'denote the acquisition of control and coordination of specific voluntary movement during infancy and childhood' (Malina, 2004), p. 52). Environmental factors influence child motor development, interacting with growth and maturation, and therefore influence the standardisation of the developmental milestone (Malina, 2004). Therefore exploring the environmental factors for specific regions might provide supportive information while investigating child motor development, and accordingly child independence.

Self-care comprises activities of daily living. Basic skills are eating, drinking, dressing, grooming, bathing, and toileting, all carried out primarily during the daily routine (Nelson, 1996). Self-care has been linked with school-age children who are expected to reach an

unsupervised level of independence and responsibility for their own safety and wellbeing (Kerrebrock and Lewit, 1999). Developing self-care skills depends on two components: ability and opportunity. This means having the ability to be engaged in self-care tasks, and the opportunity to perform these tasks by creating environmental pressure that promotes the performing of skills (Kellegrew, 1998). It has been suggested that developing self-care skills depends on family and culture, the family's socioeconomic status, and the child's characteristics (Kellegrew, 1998).

Mastery of mobility and self-care tasks encourages the child to socialise, allowing him or her to practice and relate to others (Liamputtong, 2007). The mastering of self-care and motor skills is interrelated as shown in the literature (Kiddoo, 2012); for example, early self-feeding and the development of gross motor skills have been shown to be associated with a high intake of most nutrients (Carruth et al., 2004). Mastery of toileting is also associated with the mastering of other self-care and mobility tasks such as sitting, walking, dressing and undressing (Liamputtong, 2007, Carruth et al., 2004). Recognising this is essential when evaluating the mastering of skills or designing developmental programmes.

A child's independence in the functional skills domains (self-care, mobility, social function, or cognitive) can be improved by challenging the child to engage in physical activities, and also by providing help for them until they attain their expected level (Savage et al., 2012, Marotz, 2012).

1.2.2 Development of independence of child with cerebral palsy

Children with cerebral palsy have developmental delays and difficulties in mastering the functional skills outlined above (Hinchcliffe, 2007, Finnie and Bavin, 1997, Miller et al., 2006). In the rehabilitation plans of children with cerebral palsy complete mastery of these skills is not the goal; rather it is to improve functions and capabilities in terms of locomotion, cognition, and social abilities in order for the child to develop independence (Krigger, 2006, Rosenbaum, 2003b). Practicing activities of daily routine when the child independently eats, dresses and carries out other tasks can be used to motivate therapies that aim to increase the child's skills abilities, mostly if the child transfers practicing the learned skills from one setting to another, for example transferring hand washing from school to home (Kellegrew, 1998). As children's progress, their functional abilities are evaluated and re-evaluated by the rehabilitation team to make sure that they develop the expected level of functional skills and progress towards independence (Østensjø and Brogren, 2003). To evaluate which movements and postures to improve or develop, task analysis is carried out by the therapist and compared with the development of children of the same age group (Levitt, 2013).

Two important factors control independence: the child's age and level of impairment (Finnie and Bavin, 1997). Some children with multiple disabilities may never become totally independent in terms of mobility. For these children, aids such as wheelchairs are available. However, for children with lower levels of disability, physiotherapists within the

rehabilitation team and parents can work together to encourage independence and the child's potential to participate in society (Rosenbaum, 2003b). When a child is performing functional activities the level of support is suggested to be at the minimum he or she needs in order to encourage independence (Griffiths, 1988). Griffiths (1988) suggested that if children with cerebral palsy were provided with too much support it would be difficult to learn the next stage of functional ability. However, children with cerebral palsy are often faced with overprotection from parents and caregivers, which in turn may lower the expected achievement level of independence development (Blomquist et al., 1998).

The treatment of children with cerebral palsy is generally aimed towards the attainment of independent walking, with this appearing symbolic of motor independency. However achieving independent walking does not exclusively reflect motor independence, because wheelchair locomotion can also be considered as maintaining independence (Bottos et al., 2001). Self-care tasks concerned with health and hygiene are taught to children, however prioritizing these tasks depends on family and cultural practices, for example in western countries mastering some self-care tasks is required for the child to participate in social activities (Kellegrew, 1998). Parents are encouraged to pay attention to their child with cerebral palsy and encourage independent activity, whilst gradually reducing their own help (Finnie and Bavin, 1997).

1.3 Beliefs

It has been suggested that people's beliefs are implicated in most of their daily practices (Domènech et al., 2010). The concept of 'beliefs' among different philosophers is however inconsistent; Hacker considers a belief to be what is *felt,* as a kind of *mental status* or *disposition* (Hacker, 2004). Hume (1711-1776, cited by Gorman (1993a) however describes belief as the act of mind where the individual gives more weight to some thoughts, which influences their emotions and imagination in a particular way or direction. Rokeach (1968) proposed that beliefs consist of three components; an affective component, which reflects emotions; behavioural components that arise with presence of actions, and cognitive components that represent knowledge. Alternatively Sigel (1985) contends that beliefs are 'mental constructions of experience - often condensed and integrated into schemata or concepts that are held to be true and that guide behaviour' (Sigel, 1985,p. 351).

These definitions demonstrate how the concept of 'belief' is interpreted by different authors (Gorman, 1993b, Sigel, 1985, Rokeach, 1968), and it might also reflect how 'belief' is understood by other people. Leatham (2006) argues that individuals cannot clearly express their beliefs, and that we cannot simply ask people directly about their 'beliefs' and expect clear answers.

The distinction between 'belief' and 'knowledge' is explicitly discussed in the literature (Österholm, 2010, Pehkonen and Pietilä, 2003, Abelson,

1979, Leatham, 2006). Leatham (2006) asserted that *beliefs* are things that we 'just believe', whilst knowledge consists of things 'more than belief – [things that] we know'. Pehkonen and Pietilä (2003) on the other hand, emphasise the importance of describing how we understand *belief*. Nespor (1987) suggests that beliefs have stronger effects than knowledge, and that knowledge of a domain differs from feelings about a domain. Beliefs can form *belief systems* that can be described as interrelated structures of norms that have variation in the degree in which they are systematic' (Borhek and Curtis, 1983). Syke (1989) suggests using belief systems as tools to observe events, communicate with people, and classify information.

In the current study the examined maternal beliefs were obtained by interpreting the statements made by the mothers during the interviews, where they gave some thoughts more weight than others, providing propositions both consciously and unconsciously, and talked about how they constructed these thoughts and propositions.

1.3.1 What is a 'belief system'?

Belief systems vary in degree, structure, and relationship to each other (Borhek and Curtis, 1983). The concept of a 'belief system' is considered to be highly confusing and used in different contexts (Abelson, 1979), so it is essential therefore to describe how belief systems are defined and understood and to clarify how they are defined and employed in the current study.

Belief systems are the stories we tell ourselves to identify how we make sense of reality and the world around us, through systemically-structured norms and beliefs (Domènech et al., 2010). Sykes (1989) suggests that people use belief systems as a tool to observe events, communicate with people and classify their own knowledge. He asserts that belief systems are composed of four main elements: feelings, thoughts, actions, and expectations, and argues that 'there is no feeling without accompanying thoughts, actions, and expectations' (Sykes, 1989), p. 98). He also suggests that belief systems are a mix that comes from the 'great outside' whether it is nation, culture, religion, neighbourhood, family and mother, and the 'great inside', how we individually interpret beliefs and convert them into personal knowledge (Sykes, 1989). Sykes (1989) acknowledges the role of feelings and thoughts in representing an individual belief system and the behaviour that can be expected when embracing one.

At the most fundamental level it is important to differentiate belief systems from knowledge and knowledge systems. A knowledge system, as interpreted by Abelson (1979), is a network of different related ideas that belong to different levels of overviews, which is processed by the human and manipulated under certain circumstances. Belief systems focus on the existence and non-existence of the concept of some entities, like the existence of God or witches. While some people hold the belief that particular entities exist, others believe they do not exist. This is usually found in belief systems and is not typically found in knowledge systems, where for example the individual might

know about the entity (e.g. witches) but not necessarily *believe* in their existence (Abelson, 1979).

Knowledge system information is stored semantically and can be expressed in logical sentences, and whereas belief systems arise episodically with materials from personal experience and culture, knowledge systems do not necessarily need such episodes, and instead rely on general principles (Abelson, 1979, Pajares, 1992). Belief systems therefore draw from a deeper realm of human experience than knowledge systems. Domènech et al., (2010) on the other hand, suggested a dynamic context of belief, experience, and reason as follows: beliefs arise from experience, which in turn requires previous beliefs and reason to be adopted. Reason needs experience to be shaped, and beliefs need reason. Beliefs, experience, and reason change constantly and are based on each other; their relationship is dynamic (Domènech et al., 2010).

1.3.2 Parental belief systems

Parental beliefs about their children's health, development, and rearing appear to be complex due to the diverse concepts of belief researchers use when investigating them. Reviewing studies that discuss the connections between ideas and behaviour in parent-child relationships, Miguel et al. (2010) suggest that belief systems are about each parent's perception and their logical analysis of their child's development. These belief systems are used to process the parents' information and explain the biases and errors of the new knowledge. Miguel et al. (2010) used

several terms in their interpretation referring to the same meaning (belief, perception, idea).

No single defining term is used by all authors; they are referred to as parental knowledge, constructs, theories, ideas, thinking, perception, naïve theories, views, attitudes or goals (Sigel et al., 1992, Murphey, 1992, Harkness and Super, 1996, Hirsjärvi and Perälä-Littunen, 2001).

Goodnow and Collins (1990) do not favour the term 'belief' and use 'parents' idea' instead, arguing that the term 'belief' raises many philosophical issues. Goodnow (1988) believes that 'ideas' do not embody the same sense of conviction that is entailed by the term 'belief', and argues that not all parents' 'ideas' carry conviction, therefore the term 'ideas' can fit a wider range of studies that investigate parental thoughts about parenting. On the other hand, Harkness and Super (1996) use the term 'belief' in their examination of the cultural aspects of parents' beliefs, assuming that the general reader may easily understand the term. 'Perception' is one of the terms that is used in explorations of the concept of what a parental belief system entails (Hinojosa and Anderson, 1991a). 'Perception' has been defined as the production of perceiving (Colman, 2009). Murphey (1992) argues that parental beliefs are affected and moderated by the parents' perceptions. Smith (2001) also reveals that perceptions are not a dispositional state but rather the acquiring of beliefs. Therefore, Hirsjärvi and Perälä-Littunen (2001) suggest that giving a clear definition of what the researcher means by 'belief' is a fundamental step that must precede any investigation of parents' beliefs.

Sigel (1985) was the pioneer of studying parental beliefs. Bringing together a collection of studies that defined the field of parental belief as a major and legitimate area for empirical study, he put these studies under the umbrella of 'parental belief systems', and research on this topic has continued to develop ever since (Sigel et al., 1992, Goodnow, 1988, Miller, 1988, Holden, 1997, Aunola et al., 2002). Sigel et al. (1992) use the generic term *parent cognition* to refer to a range of terms including belief, thought, and idea to encompassing parental belief systems; however, *parent's cognition* is still a general term to describe their beliefs.

McGillicuddy-De Lisi and Subramanian (1996) state that beliefs are constructed, and parents integrate personal experience through social meaning. Sigel's (1985) definition of belief was adopted in this study. He states that beliefs are 'mental construction[s] of experience, often condensed and integrated into schemata or concepts that are held to be true and guide behaviour' (Sigel, 1985,p. 351). Parents' beliefs are influenced by several factors that can manifest as a set of beliefs and produce belief systems.

Murphey (1992) reviewed studies that investigated the beliefs of parents of able-bodied children, and their influence on the parents' behaviour and subsequently that of their children. He argues that parental beliefs indirectly affect the children's outcomes by influencing parental behaviour; this strengthens the importance of understanding these parental beliefs, especially in the cases of parents of disabled

children who need continuous training (parent's behaviour) and special focus on the children's development (child outcome).

To investigate parents' beliefs about their children, Miller (1986) recommends four questions to guide the focus of the research: (1) what are the beliefs? Focusing on the origin of these beliefs, the second question is: (2) what experiences did the parents go through to form and modify their conceptions of their children? (3) What is the relationship between a parent's beliefs about a child and their behaviour towards the child? (4) How does a parent's belief relate to the measure of the child's development? Because the current study aimed to examine and identify parental belief systems, the focus while collecting the data was mainly on the first two questions, which investigate the beliefs and the experience behind these beliefs. However, when needed, the parents' behaviour toward their children and the children's developmental measures represented by the third and fourth questions, could be highlighted to enrich the interpretation of the data analysis.

1.3.3 Parental child rearing beliefs and child independence

According to Suizzo (2002) study, independence could simply capture the wide variation in parental child rearing beliefs. Greenfield et al. (2008) investigated the difference of the belief system between mothers and nannies who came from different cultures; the study proposed that their beliefs regarding the development of independence formed part of the area of child rearing beliefs. Hirsjärvi and Perälä-Littunen (2001) reviewed the literature about the child rearing beliefs of the parents of able-bodied children and found that investigations should be carried out

on their beliefs, as they were the main indicators of their decisions throughout their lives. Their review discussed several aspects of child rearing beliefs, and found that even if the parents were familiar with a belief it did not mean they were converted to believing it. Most of the studies were responses to Miller (1986) study, which were clarified in Section 3.2.3, parental child rearing beliefs mainly focused on the nature of child development and the children's abilities. For instance, they found that mothers were moderately accurate in evaluating their children's abilities, and able to tolerate their son's aggression. The review also revealed that a child's personality and actions affected the parents' beliefs, and suggested that whilst questioning the parents about their children's beliefs, researchers should endeavour not to explore the views of children in general (Hirsjärvi and Perälä-Littunen, 2001). Hirsjärvi and Perälä-Littunen (2001) also emphasised that when parents think about their own child, the child's personality will influence their beliefs. Murphey (1992) on the other hand, argues that children adopt their parents' beliefs, and therefore, a child's outcome in terms of the use of mental abilities like memorising, categorising, social interaction, and problem solving, are found to be affected by their parents' beliefs. Murphey (1992) believed that this happened indirectly through the child's influence on its parents' behaviour. This finding also highlights the importance of investigating parental beliefs regarding their children to enrich our understanding of a child's level of independence. Hirsjärvi and Perälä-Littunen (2001) review clarified the relation of parental child rearing beliefs with the children's outcomes; however this

review was conducted among able-bodied children. On the other hand, according to the review conducted by Raya et al. (2013), parenting style and practice is different for the parents of disabled children. This review encouraged a focus on the child-rearing beliefs of the parents in the current study, as it illustrated enriched knowledge about parental beliefs in relation to the development of the children's independence. It was found that being protective and permissive are two of the main characteristics that are found in parents of children with disability that may reduce their children's decision-making development and thus make them more dependent (Raya et al., 2013). This also encourages a focus on this area of the parents' beliefs to explore how it can be related to their beliefs regarding their children's independence.

1.4 Overview of Saudi Arabia

The modern state of Saudi Arabia, founded by King Abdul Aziz Bin Abdul Rahman Al Saud, is one of the largest countries in Asia and the Middle East and is located in the heart of the Arabian Peninsula (The World Factbook, 2017). The country is divided into 13 regions with its eastern region (province) being the largest on the map. This is called Ash Sharqiyah (Nawwab 2017) Figure 1.1.



Figure 1.1. Map of Saudi Arabia showing its eastern province (Ash Sharqiyah)

The most recent census data for Saudi Arabia shows a population of over 32 million, of which 37.31% are non-Saudi (General Authority for Statistics, 2017). Amongst the 20,427,000 Saudi population, Table 1.7 below shows the percentage of each age group; around 30% of the Saudi population is made up of children below 14 years old (General Authority for Statistics, 2017).

Age	Percentage of population
0-4 year	10.4
5-9 years	10.4
10-14 years	9.3
15-19 years	8.7
20-40 years	35.4
41-60 years	18.9
Above 60 years	6.5

Table 1.7. Percentage of each age group among population (General Authority for Statistics, 2017)

Saudi health services have been developed over the recent decades, and prioritized by the government (Almasabi, 2013). Almost two decades ago the Saudi health care system was ranked 26th among 190 health care systems according to the World Health Organisation (World Health Organization, 2000), while ranked 19th out of 51 nations according to Bloomberg analysis for the most efficient health systems (Bloomberg, 2014). The Ministry of Health (MoH) is the major financier of health care services in Saudi Arabia, with a total of 282 hospitals and 2361 primary health care centres (Health statistical year book, 2017). Public health services cover 60% of the health services in Saudi Arabia, and 20% is served by other government agencies such as the Ministry of Defence and Aviation (MODA), Ministry of Education (MoE), the

Saudi Arabian National Guard (SANG), the Ministry of the Interior (MoI) and the Red Crescent Society. These agencies provide health services to their employees. The private sector contributes the remaining 20% of healthcare provision, primarily in the big cities, with 125 hospitals (Ministry of Economy and Planing, 2010, Albejaidi, 2010, Almalki, 2011).

Public health services are provided by MOH on three levels as illustrated in Figure 1.2 (Almasabi, 2013).

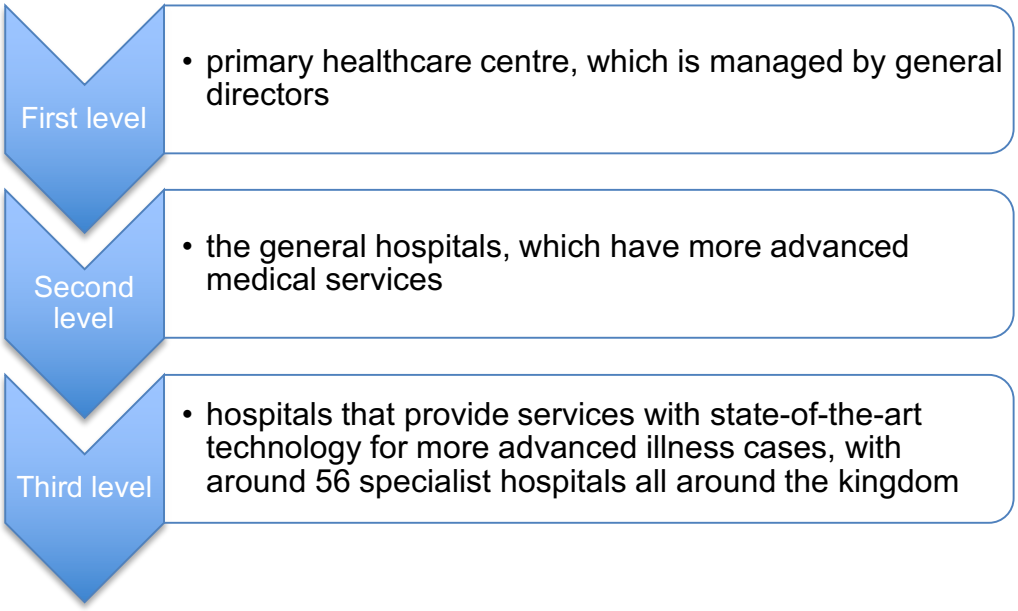


Figure 1.2. Public health service levels (Almasabi, 2013).

All public MoH hospitals and other governmental agencies offer rehabilitation services for people with special needs under the umbrella of the Ministry of Labour and Social Development. There are day care centres that provide public services and programmes for disabled people for limited periods of the day. These include social, psychological, health and recreational programmes, as well as family

guidance and education programmes. The ministry also provides care and rehabilitation programmes for disabled children and adults, including physical therapy, occupational therapy and the practicing of different daily skills. These centres were established to be an option for families that wanted to have support in taking care of their disabled children. There are 12 government rehabilitation centres and 120 private rehabilitation centres distributed in the major cities of Saudi Arabia, serving 433,511 individuals with disabilities (Ministry of labor and social development, 2017).

1.4.1 The role of religion and culture in Saudi Arabia

Saudi Arabia is the birthplace of Islam. There are two holy cities located in the country: Mekkah with the Kaabah, the believers' destination for prayer and performing Hajj (pilgrimage), and the city of Madinah, the resting place of the prophet Mohammad, the messenger of God (Vassiliev, 2013). Religion in Saudi Arabia has a wide definition and from the beginning Islam has been the foundation of people's lives. Saudis tend to consider their religion as a life system, and the basis of their values and law; their private and public lives are full of Islamic beliefs (Ochsenwald, 1981, Al-Husayyin, 2010). The rule of the Saudi royal family was established on a religious basis and legitimised by Islam (Ochsenwald, 1981, Nevo, 1998), and Saudi Arabia bears the responsibility to support Islam and defend it worldwide (Al-Husayyin, 2010, Ochsenwald, 1981).

In Islam 'Allah' is the Arabic name for God. The most important and basic Islamic teaching is belief in the oneness of God (Ahmad, 1998,

Rassool, 2000). The Qur'an is the Muslim holy book, and Muslims believe it to be God's words, while Hadeeth is the words of the prophet Mohammed the messenger from God who called for Islam. Qur'an and Hadeeth are the only two sources of Islamic teaching that Muslims believe and follow (Rassool, 2000, Al-Husayyin, 2010).

Islamic teaching is integrated into many aspects of peoples' lives, and as such Islamic religious beliefs have shaped Saudi culture in many aspects (al-Shahri, 2002, Rassool, 2000). Islamic teaching guides peoples' beliefs regarding health and illness, encouraging the understanding that illness is not a human enemy but rather a mechanism to purify, cleanse, and obtain physical, emotional, and spiritual balance; it is a part of life and a test from Allah (Rassool, 2000). In Islamic teaching, complaining about illness should be avoided, while satisfaction and acceptance is encouraged, along with asking Allah to reduce suffering (Aljibaly, 1998). At the same time, seeking treatment is encouraged according to the prophet Mohammad's words: 'Seek treatment, because Allah did not create a sickness but has created a treatment for it except for old age' (Rassool, 2000) pg.1481. Caring is a concept that is emphasised in Islamic teaching, as it reflects the notions of responsibility, motivation with concern, sensitiveness, and commitment; there is high expectation from Muslims to be merciful and compassionate to each other while believing in obtaining the compassion of Allah (Rassool, 2000).

The influence of culture is, of course, apparent in people's life in Saudi Arabia and is manifested in its traditions and customs. Although Islamic

beliefs have had an impact on Saudi culture there are many traditions that have developed uniquely within Saudi society (Ezzi et al., 2014). Saudi society is considered to be conservative, and the path toward a more progressive society is being trodden very carefully (Hamdan, 2005). For example the policy of gender segregation is officially followed in most government sectors in Saudi Arabia, and many families choose separation during social gatherings, believing that females feel more comfortable in female-only environments (Alhujaylan, 2014).

1.4.2 The family in Saudi Society

The family is the fundamental unit and the main foundation of Saudi societal organisation. Islamic beliefs have influenced the family structure and relations (AlMutair et al., 2014, Almunajjed, 1997). Islamic teaching guides family relations socially and emotionally, providing a commitment between family members. Saudi families extend beyond the nuclear family of the first generation to the bigger family of second and third generations, and this provides them with a sense of identity (AlMutair et al., 2014, Luna, 1989). Moreover, Saudi women's social and physical mobility is restricted due to a lack of decision-making power, limited economic and political rights, restricted use of public transportation, and not being allowed to drive (Hamdan, 2005, Doumato and Posusney, 2003). Moreover because of having less access to employment and economic opportunities, participation and rights are limited (Kelly and Breslin, 2010).

The mother is preferred over the father in some aspects of Islamic teachings; there is a belief that ‘paradise lies at the feet of mothers’, and according to Islamic teachings the prophet Mohammad gave the mother three times the value when compared to the father, when a man asked him to whom he showed show most concern and kindness (Almunajjed, 1997). The position of women in Saudi Arabian society differs from other Islamic communities, placing emphasis on conservativeness. This is complicated by the confusion between Islamic teaching and Saudi Arabia’s strict societal traditions; although Islam ensures woman have equality with men in many social, economic, and political areas, the power imbalance between men and women in Saudi Arabia is obvious. Every woman is required to obtain authority from their nearest-related male guardian regardless of their age, by law on one side and the structure of society on the other (Hamdan, 2005). This influences female mobility abroad, including having the opportunity to obtain higher education from other countries (Alhareth et al., 2015). Moreover women’s lack of access to the justice system forces them to rely on men to represent them.

All of this gives men the power to control women’s capabilities (Alhareth et al., 2015). Islamic teaching, however, gives the woman a greater role as a mother than the man has as a father; the mother is considered to be the maker of the home and the main nurturer. The father, or the family man, acts as the leader of the house, the protector and spokesperson; he is responsible for the family finances and earning the family income, and is the primary – but not the only – decision maker.

Managing the house, doing the household chores, taking care of the children and the family's social life is the mother's responsibility, and in recent years some mothers have also shared the burden of financial support, increasing their workload (Almunajjed, 1997, AlMutair et al., 2014, al-Shahri, 2002, Hamdan, 1990).

1.5 Conclusion

This chapter has set the context for the study, describing cerebral palsy, its causes, and prevalence, and the impact of the condition on a child's functional and cognitive skills. The aim of cerebral palsy treatment to ensure maximum independent function through rehabilitation has similarly been discussed. This chapter has also described the kingdom of Saudi Arabia's healthcare system, religious and cultural beliefs, and how these are manifested in daily life.

2 Chapter 2: Literature Review

This chapter reviews the literature that underpinned the current study, starting with a description of the search strategy that was used to identify the relevant studies. After that, a review of studies that investigated the parental beliefs of disabled children will be set out. The literature review assisted in the identification of relevant evidence gaps, which in turn guided the choice of research question.

2.1 Aim of the review

The aim of this literature review was to find existing literature investigating the beliefs of the parents of children with cerebral palsy or other physical disabilities and to identify any relation with these disabilities and child independence.

2.2 Search strategy

To be included in the literature review studies needed to have information about parents of children with disabilities, especially children with cerebral palsy. It is recognised that the parental beliefs of able-bodied children was a potential area to explore, as explained in the last chapter (Section [1.5.2]). However this study is intended to explore the parental beliefs of children with disabilities, to discover the areas that were investigated and to highlight any research gaps especially concerning the beliefs of parents of children with cerebral palsy with relation to their beliefs regarding independence.

In order to retrieve all appropriate literature the following databases were searched: Pubmed, ASSIA (Applied Social Sciences Index and Abstract), CINAHL, Psych INFO, Web of Knowledge, Web of Science, AMID Allied and Complementary Medicine (OVID), SCOPUS, and Google Scholar. The reference lists of relevant articles were also scanned for additional studies, and online published theses relevant to the study were also reviewed through Google scholar. The search was carried out from November 2013 to March 2014, and was updated in April 2018.

The primary search with the main key words used truncation symbols (e.g. *) and the three basic Boolean operators (OR, AND, NOT). The main key words were:

- Belief/s;
- Parent/s;
- Child;
- Cerebral palsy;
- Independence.

The search used Mesh- terms and/or word text terms, In every database main key words were used first for searching, then synonyms and broader terms were used to expand the search; these terms were clarified using the on-text PEO (population, exposure, outcome) format, as it is more popular in qualitative research (Butler et al., 2016). As shown in Table 2.1 below, terms were adapted per database as required. Titles were scanned then related studies were downloaded.

	Population	Exposure	Outcome
Concept **(main key word)**	Parent Children Cerebral palsy	Belief/s	Independence
Synonyms	Mother Maternal	Belief system Parental belief system	Childrearing
Broader terms	Disability	Perception	Functional activity
Related terms	Woman Family	Arab Saudi Arabia	Health Culture Religious Islam Stigma

Table 2.1. Key words using PEO format.

Studies were initially selected by screening titles and abstracts according to the inclusion criteria (illustrated in Table 2.2 below).

Inclusion criteria	
Language	Published papers in English.
Years of publication	Because of the limited literature, the was no date limit for published paper
Study design	Qualitative and mixed-method.
Phenomenon	Information regarding parental beliefs regarding children with physical disabilities.
Perspectives	Only parental beliefs are included in the search.
Population	Papers that investigate parents' beliefs concerning children with mild and moderate disability in the age range 6.5 to 14 years (age of expected independence as explained in study methods section [3.3.2])

Table 2.2. Search inclusion criteria.

Forty-two studies were downloaded, then after reading the studies' abstracts, 32 studies were excluded for different reasons (Table 2.3).

Study	Excluding reason
(Baker et al., 2005); (Sen and Yurtsever, 2007, Knox, 2008, Baird et al., 2000) (Rentinck et al., 2010) (Leerkes et al., 2010); (Yeh et al., 2004);	Quantitative study
(Hebert and Koulouglioti, 2010); (Jansen et al., 2003); (Kruijsen‐Terpstra et al., 2014); (Russell, 2003).	Review research
(Roskam, 2005); (Teachman and Gibson, 2013); (Gething, 1985); (McConachie et al., 2001).	Sample: children not in the age range
(Croot, 2012); (King et al., 2006); (Rodriguez and Olswang, 2003); (Skinner et al., 1999); (Marteau and Johnston, 1986); (Morrow et al., 2012);	Sample: children with non physical disability/ children with general disability
(Degotardi et al., 2008); (Raeff, 2000);	Sample: able-bodied children

(Kai, 1996); (Senese et al., 2012); (Leerkes et al., 2010); (Zvara et al., 2013).	
(Croot et al., 2008); (Green, 2007); (Bedell et al., 2011)	Investigate parental experience, perspective

Table 2.3. Excluded studies.

It was necessary to ensure the sensitivity and specificity of the search to have at least the following key words in the title: mothers, fathers, parents, disabled children, cerebral palsy, and beliefs. It is worth noting that none of the studies was found to have the key word 'independence' along with the other main key words in the title. The search revealed ten studies that were able to be included in the literature review; four of them investigated the beliefs of parents of children with cerebral palsy or of parents of children with general disabilities. Moreover, because there is a focus on children with cerebral palsy, there was an exception made in including two studies that investigated parental 'perceptions' (Hinojosa and Anderson, 1991b, Morgan and Tan, 2011a, Morgan and Tan, 2011b) and two studies that investigated parental 'experience'(Huang et al., 2010, Mir and Tovey, 2003). Also although Crabtree (2007b) and Raman et al. (2010b) investigated parental perceptions of children with disabilities they were included because they

were conducted in Arabian Gulf countries in order to be able to capture parental perceptions in relation to child disability in an Arab context. The quality of the revealed studies was assessed using the mixed method appraisal tool (MMAT version 2018) (Pluye et al., 2009, Pluye, 2011). The selected studies contain one study with a mixed method design (Gannotti et al., 2001) while the rest of the studies were qualitative studies. The MMAT is an assessment tool that is suitable for all research designs and was chosen to maintain congruence in the assessment of research quality. The MMAT scoring ranges from 0% (study does not meet any of the criteria) to 100% (study meets all the criteria). In the current study, studies that achieved 40% and above were accepted and included. The studies that were included in the review are shown in Table 2.4 below.

Study	Country	Purpose	Sample	Method	Conclusion	Limitations	MMAT Scores
Hinojosa and Anderson (1991)	United States.	Explore mother's perceptions of home treatment programmes for their preschool children with cerebral palsy.	Eight mothers of children with cerebral palsy.	Intensive interviewing techniques; each mother interviewed twice.	Mothers' descriptions suggest that they could integrate treatment techniques and strategy into their daily routines and interactions.	The study focused on mothers' perceptions of the home programme and reflected little on what they may believe about their children's independence.	**
Mir and Tovey (2003)	England (Asian carers).	Understand South Asian carers' experiences with particular emphasis on the nature and impact of professional-lay interactions from the perspective of service users.	20 carers of children with cerebral palsy.	Semi-structured interviews.	Developments in service provision need to build on the perspectives of South Asian individuals and communities to respond effectively to their needs.	The study focused on the carers' experience about services as a minority group in the UK. It also reflects some health beliefs. The study did not discuss parent-child relationships.	****
Saul and Phillips (1999)	Nepal.	Explore the cultural beliefs and actions concerning cerebral	40 mothers/teachers of children	Observing, interviewing, and holding	There are complex relationships between different	Focused only on the cause and understanding of disability.	**

		palsy and similar conditions of parents and families of children with cerebral palsy; medical, healing and other professionals working with the children; and, where possible, the children themselves.	with cerebral palsy and the children themselves.	discussions.	belief systems, the health care system and cultural belief systems. People can be reticent to discuss their beliefs and their own cultural categories.	Omitted beliefs regarding parent-child relations.	

Gibson et al. (2012)	Canada.	Describe beliefs about the value of walking held by children with CP and their parents, and to examine how these beliefs inform rehabilitation choices and perceptions of 'success'.	Six children with cerebral palsy and six parents.	Face-to-face individual qualitative interviews were conducted using a flexible, semi-structured interview guide.	The results of this pilot study provide provisional evidence regarding how dominant social values regarding walking and disability are taken up by parents and children. They suggest that rehabilitation programmes need to consider how they may unintentionally reinforce potentially harmful choices, and how best to engage families in discussions of their evolving values and treatment priorities. Further research is needed with a larger sample.	The research focused on one functional activity (walking), which will provide some of their beliefs regarding independence, but is not comprehensive. Research did not discuss parent-child relationships.	****

Gannotti et al. (2001)	Puerto Rico.	Describes culturally-defined meanings of childhood function and disability in Puerto Rico to provide a context for the interpretation of test scores from the Spanish translation of the Pediatric Evaluation of Disability Inventory (PEDI).	44 parents of children with and without disability (spina bifida). Age (6m-8y). 391 respondent (childhood function questionnaire) 218 respondent (attitude about childhood disability	Open-ended interview (clarifying beliefs and pattern of behaviours); Questionnaire on typical childhood function; Questionnaire on attitude about childhood disability.	Quantitative and qualitative data analysis confirmed that differences exist between Puerto Ricans and the norms established in the US for the performance of functional skills by children. The analysis also described Puerto Rican beliefs and attitudes toward disability.	Sample was of parents of children with spina bifida, which differ in characteristics from children with cerebral palsy.	****
Morgan and Tan (2011)	Cambodia.	Explored the beliefs of Cambodian parents of children with cerebral palsy regarding disability causation and their perceptions of the effectiveness of	22 parents or carers of children with cerebral palsy.	Semi-structured, individual and small group interviews.	The complexity of Khmer belief systems was reflected in the range of participants' perceptions of the cause of their child's	The research focused on the cultural aspects of parents' beliefs. Research did not discuss parent-child relationships.	****

		interventions in bringing about change in their child.			disability, yet beliefs around disability causation did not appear to have determined their care-seeking behaviour or their perceptions of effectiveness of interventions.		
Crabtree (2007)	United Arab Emirates.	Explore mothers' perceptions in relation to family and social inclusion issues, and parental views of existing provision with regard to services for children with special needs in the region.	15 mothers of disabled children (autism, Down syndrome, microcephalism, learning disabilities).	In-depth open-ended interviewing technique.	In common with other middle eastern countries social stigma is prevalent and this impacts disabled children and their mothers, however this ameliorated by the influence of religion, which constitutes an example of family resilience.	Study was of different disability types, none of which was cerebral palsy. The researcher is not from the same the culture as the country where the research was conducted. The research focused on the cultural and social aspects of mothers' beliefs.	**

Raman et al. (2010)	Kuwait.	Examine perceptions of mothers of children with disabilities in Kuwait in order to understand the meaning of disability from their perspective and explore the extent to which such perceptions influence the rehabilitative services that their children receive.	10 mothers of children with disability (cerebral palsy, congenital defect in the pelvis, hemiplegia, quadruple paralysis).	Semi-structured face-to-face interviews.	Findings suggest that despite a traditional acceptance of disability as divine intervention or a challenge sent from God, mothers were motivated to maximize rehabilitation services in order to improve the functional capacity of the children.	The researcher is not from the same the culture as the country where the research was conducted. The research focused on the meaning of disability and reflected the religious and cultural aspects of their beliefs, also their beliefs toward the services (rehabilitation centres). The research did not discuss the mother-child relationship.	***
(Morgan and Tan, 2011b)	Cambodia	This study examined the perceptions of parents living in rural Cambodia regarding family-centred rehabilitation practices.	Convenience sample of 24 parents of children with cerebral palsy from three rural provinces	Qualitative study using a multiple case-study strategy	Family-centred approaches to paediatric rehabilitation were found to be valued in and appropriate for a rural Cambodian context. Social and cultural mechanisms to be considered when	The sample included children in a wide range age from 3-12 years, included children of ages where independency is not expected. Investigating the rehabilitation process did not include details about developing child functional	****

					adapting a Western, family-centred model of rehabilitation planning to rural Cambodia.	skills and independence.	
(Huang et al., 2010)	Taiwan	This study is a report of a study describing mothers' experience of learning that their child has been diagnosed with cerebral palsy.	15 Taiwanese mothers of children diagnosed with cerebral palsy	Hermeneutic Phenomenological study Using in depth interviews	To promote better understanding of the child's condition, emotional support and information should be provided to the mother and family, both when informing them of the diagnosis and in the period after diagnosis.	The study focused on the mothers' feeling after learning the diagnosis, and did not provide information about their thoughts regarding child possible functional abilities and expected independency.	***

Table 2.4. Summary of reviewed studies of parental beliefs and perceptions of children with physical disabilities

2.3 Literature review

In order to explore parents' beliefs about their disabled child's independence, it was pertinent to review literature that investigated the beliefs of parents of disabled children from various perspectives and to find any related links with their beliefs regarding independence. Moreover because of the limited amount of literature that was found, studies that investigated parental perceptions were included because of the similarity between perception and belief (Murphey (1992), although acknowledging the further depth that beliefs provide.

Investigating the beliefs of the parents of disabled children to find possible links with their beliefs about child independence revealed studies that focused on parental beliefs regarding the meaning and causation of disability, and studies that explored cultural and religious impacts on parental beliefs. Moreover, some studies captured the parents' beliefs about the unique skills of the professional and their behaviour toward independence. This will be detailed in the following sections.

2.3.1 Understanding of disability

While reviewing the literature, it was essential to find studies investigating parental understandings of the meaning and causation of disability as one of the earliest areas to be explored. Four studies examined this (Gannotti et al., 2001, Mir and Tovey, 2003, Morgan and

Tan, 2011a, Saul and Phillips, 1999) (see Table 2.3) but there was no consensus identified in terms of parental views of the causation of their child's cerebral palsy.

The study by Mir and Tovey (2003) conducted in the UK, investigated the views of South Asian parents and found that they believed that their child's brain was 'damaged' or in one extreme case a mother was told that her child had 'no brain'. It appeared that they had learned these descriptions and obtained their understanding of the cerebral palsy causation from professionals at the hospital. At the same time they had not received any information about which of their children's functional areas was damaged. This would not help the mother to be able to expect what abilities the child can develop to improve their independence and be motived for training. The parents in Morgan and Tan's (2011) study similarly expected to know about their children's disability from the professionals and few of them mentioned that they received information about their child's disability. Parents of children with moderate and severe disabilities had less information than parents of children with mild cerebral palsy and they perceived that staff did not want to be the source of bad news. While the author mentioned that parents valued this information regarding their children's disabilities, in order to understand the children's treatment, there was no details about what treatment the mothers wanted to understand and if it was related to child independence.

Saul and Philips (1999) conducted a similar study to explore cultural beliefs and actions concerning children with cerebral palsy amongst 40

caregivers, teachers, and children, through interviews and observation. Although this study focused on cultural and religious factors, some of the results revealed that the mothers attributed their children's disabilities to their own ill health during pregnancy or the child's illness after birth. This study investigated parents' perceptions of the causes of disability and how they understood and named it. They attributed the cause of the disability to various factors: the parents' or children's sins in a previous life; the mothers' poor diet, illness; contact with other disabled children during pregnancy; possession, or curses. Similarly, in Morgan and Tan's (2011) exploration of parental beliefs (2011a), the participants stated that extended family and the surrounding community offered a justification for the occurrence of cerebral palsy. They most commonly believed that it was caused by a spiritual force or karma and labelled the disability as '*skan*'.

In the study by Mir and Tovey (2003), the parental beliefs pointed towards internal causes – brain damage or 'no brain' – while Morgan and Tan (2011a) revealed external causes, such as the mother's diet, illness and so forth. While in Saul and Phillips (1999) and Morgan and Tan's (2011) studies the parental beliefs placed more weight on the responsibility of the mother for causing the disability, they did not explore whether this had an impact on the parents' beliefs regarding the mother's role in the child's functional development.

Saul and Phillips (1999) classified disability into various categories: not-normal, yes-disabled and non-normal, yes-disabled but normal. They found that the participants believed that mental disability was more

associated with categorizing the children as ‘yes-disabled’. This revealed that the understanding of disability in this study linked the disability with mental more that physical disorders. Also the terms used in describing disability appear to be general, convey negative tones, and do not reflect the children’s functional abilities and independence at the same time. This could provide information indicating that the participant does not associate disability with functional abilities and independence. Moreover this is an old study that investigated parental beliefs in Nepal at the end of the 1990s, and there has not been any further research since that provides knowledge regarding parental beliefs.

In Gannotti et al.’s study, the understanding of disability was sparsely detailed; it was found that the families believed that children with chronic disabilities were ‘sick’, and were perceived to be more dependent on their caregivers than able-bodied children. The researchers argued that the parents’ general belief was that a disabled child is fragile, has a greater risk of illness, needs care for its entire life, and may die easily. However in both previous studies these beliefs did not provide more understanding about parental beliefs regarding the children’s functional abilities and independence.

In the previous studies the focus was limited to the cause and understanding of disability in general, and the children’s independence was not investigated. Mir and Tovey (2003) explored perceptions, which although indicative provide less depth of knowledge than actual beliefs

(Murphey, 1992, Colman, 2015). Gannotti et al. (2001) and Saul and Phillips (1999) focused on the cultural aspects of parental beliefs.

2.3.2 Impact of culture and religion

The current review shows that culture and religion have an impact on several aspects of parental beliefs about disabled children. Saul and Phillips (1999) linked cultural beliefs to the meaning and causation of disability. It was found that the rural-cosmopolitan continuum in Nepal allowed for complex cultural beliefs that were firmly based on traditional values. The values of rural cosmology were influenced by ghosts, spirits, and witchcraft, while urban cosmology relied upon the written word to influence its belief systems. Parents with cosmopolitan cosmologies had been exposed to modern biomedical techniques such as child vaccination, physical therapy, and occupational therapy. However their outlook was still characterised by adherence to religious beliefs and practices, besides other dimensions of understanding including individual beliefs of the family that might be embedded in traditional folklore. At the same time other parents might be influenced by their cosmopolitan experience, however Saul and Phillips (1999) mentioned that the boundaries between cosmologies are not clear and participants might hold different, and in some cases contradictory, beliefs.

The findings of this study emphasized the role of cultural beliefs in guiding parental beliefs about their children's disability and practice toward treatment. This agrees with the findings of Morgan and Tan (2011a) who found that the majority of participants reported having

traditional interventions in their rehabilitation programmes, including traditional healers saying prayers and spitting into medicines. Although the study did not find any links between these traditional cultural beliefs regarding disability causation and care-seeking, it did find that the parents' cultural beliefs about healing and intervention played a role in the training process of their children. Both studies focused on how cultural beliefs might influence the parents' choices of treatment for their children, however they did not provide any information about how the parents' cultural beliefs might influence their beliefs about their children's independence. On the other hand, Gannotti et al. (2001) found evidence of the influence of cultural beliefs on parental beliefs regarding the development of their children's functional abilities. The findings revealed that pampering and nurturing were important values that shaped the Puerto Rican parents' behaviour with their children. According to Puerto Rican values, mothers must be strong to endure the dependence of the burden of the disabled child, and the child is a gift from God and has the greatest need of care (Gannotti et al., 2001). The study briefly linked parental cultural beliefs with the child's chances of developing functional activities, but this is only one aspect of the research and does not provide comprehensive understanding of the parents' beliefs about independence. Moreover it had a specific cultural context, focusing on the influences of Puerto Rican culture on parental beliefs. This is the only study in the current literature that linked parental cultural beliefs with children's functional abilities, therefore it was not

possible to compare the parental beliefs in the Puerto Rican cultures with parental beliefs in other cultures.

Two studies (Crabtree, 2007b, Raman et al., 2010a) were conducted in the Arabian Gulf region on children with different disabilities, including cerebral palsy, showing how religious (Islamic) and cultural beliefs influenced parental beliefs. In the first study of Crabtree (2007b) found that the acceptance of the child's disability stemmed from accepting Islam. The mothers believed it to be part of 'believing in God', and the researcher found that strict Islamic values promoted understanding and tolerance of disability. The mothers also believed that according to their religious beliefs, accepting their children's disabilities was very important in maintaining their position in the family.

In the other study (Raman et al., 2010a) – which also captured some of the parents' religious beliefs regarding their disabled children – the majority of the mothers in the sample were aware of the medical condition of their child. However, they believed that God had chosen them to take on the responsibility of raising a disabled child, and that their child was given to them by divine intervention. Some mothers believed that this was a test from God. This study, therefore, found a strong connection between perceptions of disability and religious beliefs. Both studies focused on how religious beliefs influenced the parents' beliefs around the acceptance of disability, but they did not investigate if these beliefs were related to the parents' beliefs regarding the children's abilities or the parents' role in developing the children's functional activities. A major weakness of both studies was that they

were conducted by researchers from a different culture, which potentially gives a low degree of *verstehen* (comprehensive understanding of the participant (Hudson and Ozanne, 1988). In the first study (Crabtree, 2007b) the researcher did not highlight the differences in cultural beliefs between the mothers in the sample, while Raman et al. (2010b) study was descriptive and did not have enough depth to enable interpretation of the data so as to reveal the parents' beliefs. Moreover both studies focused on the mothers' beliefs about disability causation, understanding, the role of the caregiver, and social attitudes, but not the parents' beliefs and understanding of their children's functional abilities and independence; this area, therefore, appears to be under-researched.

2.3.3 Unique skills of the professional

It was found in some studies that mothers believed in the unique skills and knowledge of the professionals and therapists. Hinojosa and Anderson (1991b) found that the mothers were convinced that therapists had unique skills, and that there was a difference between a mother's treatment and a therapist's treatment in term of their techniques and knowledge. The mothers in this sample mentioned that they developed their own therapeutic program to fit their home life, believing at the same time that there were exercises that should only be carried out by the therapist. It should be also recognised that this is an old study and the maternal beliefs should be considered with caution.

Mothers in Gannotti at al.'s (2001) study were attracted to the idea that their children could learn functional skills in rehabilitation centres, but at

home they felt too sympathetic towards their children to push them to be independent. In this study it seems that the mothers believed that training the child was the role of the therapists in the rehabilitation centre, while the mothers in Hinojosa and Anderson (1991b) wanted the therapist to take on this role because of their unique skills. In Gannotti et al. (2001), training the children at home in activities that might cause discomfort to the child went against the parents' beliefs of nurturing and pampering the child, which limited their role in training the child, and in turn the opportunity to develop functional skills. Gannotti et al. (2001) reflect an aspect of parental beliefs regarding children's independence, showing that parents prioritize protection, which might limit the children's opportunities to perform functional activities independently. This study showed limited investigation in parental beliefs regarding independence; there was no detail about the parents' beliefs regarding the development of independence in different functional skills.

In Huang et al. (2010), the mothers believed that the healthcare professionals were careless, did not have enough knowledge about their children's cases and they were not sure that their children are having enough assessment. They also believed that this delayed their children's chances for treatment, which left them angry and powerless. The mothers in this study did not mention what treatment they were worried about and if this was linked to a delay in their child developing functional activities and therefore independence. Unlike the parents in Morgan and Tan (2011b) study, who showed trust for the profession by preferring to work closely with them, the parents in Huang et al. (2010)

believed that they should have been collaborating with the healthcare staff, especially in planning rehabilitation goals. At the same time there were no details concerning what the mothers expected as goals in the rehabilitation plan, and if mothers highlighted the children's development of independence.

Mir and Tovey (2003) suggested that professional attitudes help to shape the parents' expectations towards their children's status and therefore their health beliefs. This study focused more on caregivers' experience of medical and social care, and their beliefs, as a minority group in this part of England, toward health services. It looked at how they placed a high value on their relationship with service professionals, and their attitudes toward cerebral palsy, focusing on the level and quality of information received by those parents and how that informed their health beliefs. However, the study did not specify the character of these health beliefs and their influence on the parent's own efforts in the training and development of their children.

2.3.4 Behaviour toward independence

While reviewing the relevant studies that investigated parental beliefs, two studies was found capturing a linkage with beliefs regarding child independence. In Gibson et al. (2012) the results proposed that walking had a symbolic value for both parents and children, and that walking was part of a preferred able-bodied body image and identity. Encouraging children with disabilities to walk reflects parental tendencies to support the independence of those children. This study investigated walking as the main functional activity; however, it also

represents part of the child's independence, which includes mobility in terms of functional activity (Donovan et al., 2005). The study findings also revealed the importance of giving children with cerebral palsy the opportunity to talk and share their experiences, fears and assumptions while training for independent walking, which in turn reflects the children's personality development. This also highlighted the value of developing the independence of the children's social activities; however the findings came from interviewing the children, so they do not represent the parents' beliefs. The study focused on a small area of child rearing in which the parents were less protective, and encouraged their children to train to walk so as to develop independence. It was a small study with a relatively small sample, recruited from a single rehabilitation centre in Canada, and although semi-structured interviews were employed the duration was unclear and the results should be viewed with caution. Interviewing a larger sample focusing on children's functional activities with in-depth interpretation of the data is needed in this context.

As discussed in previous themes, Gannotti et al. (2001) was one of the studies that explored parental beliefs about independence by focusing on the parents' expectations, revealing that the parents believed that disabled children need to be dependent and overprotected. The researchers found that these children could not easily separate from their mothers because the interdependence between them was more intense (Gannotti et al., 2001). This study focused on exploring parental beliefs about the children's disability etiology, expectation of survival,

the social role of disabled children, the concept of the caregiver's role, and expectations about the children's performance and capability. Their findings revealed a side of the parents' childrearing beliefs that might link to their beliefs regarding independence, but the focus of the study was not on detailed parental beliefs regarding independence. It is important to note that the children's disability in this study was spina bifida, which has different functional impairment criteria to cerebral palsy (Gannotti et al., 2001).

2.4 Conclusion

The beliefs of parents towards their children with cerebral palsy are broad, as is the field of study. For this research, the concept of parental beliefs was introduced using the concept of 'parental belief systems'. Some of the many facets of these beliefs have been previously investigated. This literature review sought to capture the relation of these parental beliefs to child independence. It revealed that these parental beliefs mostly lie in four areas: the causation and meaning of disability; the impact of culture and religion; the unique skills of the professionals, and behaviour toward independence. It was found that in some cases the parental beliefs about the meaning and causation of disability were either derived from professional opinion, or from cultural beliefs. Cultural beliefs were also found to influence treatment plans in some cultures in terms of intervention choice or in beliefs regarding the parental role. Some studies also clarified parental beliefs about the special skills of professionals or therapists, which may reflect their

beliefs towards their role in the rehabilitation programme. In other studies, limited aspects of parental behaviour toward independence were discussed without focusing on parental beliefs. Cultural beliefs regarding independence were captured, although this was investigated within specific cultural contexts. This literature review uncovered several research gaps, which will be clarified in the next section.

2.5 Identification of research gaps

Although there is growing body of literature investigating the parental beliefs of parents of disabled children, research exploring parents' beliefs about their disabled children's abilities and training to develop their functional skills in general, and their beliefs specifically relating to the development of independence is still scarce. To date no studies have explored parental beliefs about the independence of their children with cerebral palsy, identifying parental beliefs by interpreting their articulations, or having in-depth focus beyond the level of the parents' expressions, to reveal beliefs that can be linked together and provide closer understanding of the parents' belief systems. The reviewed studies that investigated parental beliefs focused mainly on the parents' understanding of the meaning and causation of cerebral palsy or disability (Mir and Tovey, 2003, Saul and Phillips, 1999), and their role in training (Hinojosa and Anderson, 1991b).

The religious and cultural beliefs of the parents of children with cerebral palsy were also recognised when exploring the parents' beliefs about the causes of their children's disabilities and the influences of society.

However, studies investigating how the religious and cultural beliefs of the parents can inform their beliefs regarding their children's potential and progress in training to develop independence, and the degree of relationship between their religious beliefs and others, are still lacking.

Research focusing on the parents' and children's surrounding environmental factors, which could influence the parents' beliefs regarding their children's development of independence is not well represented within the literature.

Two studies of the Arabian Gulf area were conducted on this subject, albeit by researchers from different cultures, which could lower the level of *Verstehen.* In light of the importance of independence in the rehabilitation process of children with cerebral palsy (Krigger, 2006), these studies did not focus sufficiently on parental beliefs, revealing a gap in the understanding of this essential area.

The current study aims to explore different aspects of Saudi parental belief systems regarding independence using a method that will provide a deep understanding of these beliefs and explain their systematic relations.

2.6 Research question

What are the belief systems of parents regarding the independence of their children with mild and moderate cerebral palsy?

2.7 Aim of the study

The aim of the study was to explore belief systems regarding the independence of children with mild and moderate cerebral palsy among Saudi mothers.

3 Chapter 3: Methodology and Research Methods

This chapter presents the methodology and research methods that were employed in the study. It begins with a description of the principle of inquiry, in the methodology section, followed by an examination of the interpretive descriptive study design, which was underpinned theoretically using critical realism. The methodology section is divided into three sections:

1. The theoretical perspective that underpins the current study, describing the research ontology and epistemology and how they relate to the research question.
2. The research methodology and its relation to the research question.
3. The research methods, illustrating the relationships between the stages. The choice of methods reflects the research question and supports the current research methodology.

3.1 Methodology

3.1.1 Critical realism: ontology and epistemology

A researcher's decisions about how to conduct their study and interpret the results are guided by an underpinning philosophy (Guba and Lincoln, 1994). In the current study, critical realism was employed as the theoretical perspective. In this section, critical realism will be

discussed in the light of the research question, explaining how it informed the research ontology and epistemology.

Critical realism is considered to fall between naïve realism and social constructionism, retaining ontological realism and epistemological constructivism and relativism (Alvesson and Sköldberg, 2010, Maxwell, 2012). Ontological assumptions focus on the nature of 'reality' and contribute to the shaping of epistemological beliefs in knowing and understanding reality; therefore, they provide knowledge of reality (Guba and Lincoln, 1994). Critical realism switches from epistemology to ontology, re-legitimising ontological questions rather than epistemological ones, based on assumptions of the nature of the reality of 'what exists' (Danermark et al., 2002).

In the current study, the starting point in selecting the theoretical philosophy was the following research question: 'What are parents' belief systems regarding their children's independence?' Naïve realism, which accepts that reality exists independently of our consciousness (Guba and Lincoln, 1994), was not expected to be compatible with the understanding of reality in the current research. Social constructionism on the other hand accepts that all knowledge is constructed through human practice then developed within social contexts (Crotty, 1998). While this agrees with the research view of knowledge as 'constructed', it also accepts multiple realities; this does not correspond with the ontological assumption of how reality is considered in the current research, where 'maternal beliefs' are viewed as one reality.

Critical realists accept that beliefs, although not observed, are part of the real world (Maxwell, 2012, Maxwell and Mittapalli, 2007). Critical realism combines ontological realism with epistemological relativism; ontological realism believes that reality exists independently from people's constructions; however this reality is not fully apprehended, it is only partially accessed. Critical realism also rejects multiple realities occurring at the same time (Bisman, 2010; Braun and Clarke, 2013; Danermark et al., 2002; Maxwell, 2012). Therefore, the 'beliefs' of the parents in this study, whether we agree with them or not, are considered the 'reality' and represent the ontological part of the theoretical perspective. However, critical realism also accepts that there are valid multiple perspectives and a constructed understanding of the world. This in turn reflects the constructionist and relativist epistemological part of the research's theoretical perspective, where the knowledge of reality is always fallible and provisional, and it is not possible to directly access the absolute truth (Danermark et al., 2002, Edgley et al., 2016).

In the current study, data collected and analysed from the mothers provided a constructed understanding and knowledge of the parental beliefs. Bhaskar (1997) explained that ontological questions do not ask whether the ideas are real, but rather what kind of reality they have. The question in the current study does not ask whether the parental beliefs are real, but rather asks about what *kind* of beliefs they are. Critical realism emphasises the distinction between reality, and people's perceptions of reality, and the knowledge contained within that reality

(Bhaskar, 1997, Bisman, 2010). Critical realists critique positivism and constructivism as reducing the ontological domain of existence to the epistemological domain of knowledge, or limitations in reality, producing what is known as the 'epistemic fallacy' (Bhaskar, 2008). In critical realism, identifying the *reality* and the *knowledge* part of the study avoids the conflation between ontology and epistemology, and the confusion of what exists with the knowledge about it (Bhaskar, 2008). The distinction between *reality* and *knowledge* is acknowledged; the *reality* is represented by the existence of parental beliefs, whether we believe them or not, while the data to be interpreted provides *knowledge* about the parental belief system.

For critical realists, the physical and social world and objects of knowledge are known as the 'intransitive dimension', while the theories humans hold about the world and production of knowledge are the 'transitive dimensions' (Edgley et al., 2016, Mingers, 2006). The distinction between these dimensions allows the epistemic relativity of science to be acknowledged, while knowledge can be socially located without losing the ontological dimension (Mingers, 2006). In this study, the knowledge constructed from the collected data, providing an understanding of the parental beliefs, represents the transitive dimension; the existence of the 'parental beliefs' represents the intransitive dimension. Although the parental beliefs – and our understanding of them – might change, their actual existence does not. While critical realism does not aim to express how to find the truth, it insists that the truth (the subject of study) comes as a layered reality.

Critical realism ontology views reality as stratified into levels. The first is an *empirical* level, where things that happen as a result of immediate experience can be observed. Then, in the *actual* level, which is broader; events may happen independently from the researcher and might be observed – or not – and also might be different from those occurring at the *empirical* level. Finally, the *real* level is where mechanisms occur and produce the observable events that happen on the surface. This is called the 'causal mechanism' (Alvesson and Sköldberg, 2010, Benton and Craib, 2001, Fletcher, 2017). In critical realism, knowledge is not gained from immediate observable events or through mirroring images from accumulated experience; it is obtained from the deep dimension of reality at the level of generative mechanisms (Danermark et al., 2002). In the current research, it is agreed that the 'parental beliefs' exist as a reality stratified into levels. The *empirical* level is the observable physical activities of the children, which reflect their level of independence, and their parents' observable stance regarding their level of independence. This represents a slim aspect of reality and cannot provide knowledge about the parents' beliefs regarding their children, and exploring this part of reality is not part of the current study. Instead, critical realism takes these observable elements and goes beyond the surface of this social phenomenon, the children's and parents' actions towards independence (Alvesson and Sköldberg, 2010). The *actual* layer of reality represents the children's actions and their parents' stances, which are not included in this study – although we still agree that they exist – as well as those events that happen in

the children's lives without the researcher's knowledge or awareness. Finally, the *real* level, also called the whole reality, can be discovered by getting into the deeper dimension (Mingers, 2006). Understanding the parents' beliefs regarding their children's independence takes place at the *real* level, when we get closer to these parents, collect the data and interpret their articulations to gain deeper knowledge about their beliefs. This is illustrated in Figure 3.1, which is adapted from Walsh and Evans (2014) and illustrates the three levels of reality as a tree (roots, trunk, and branches).

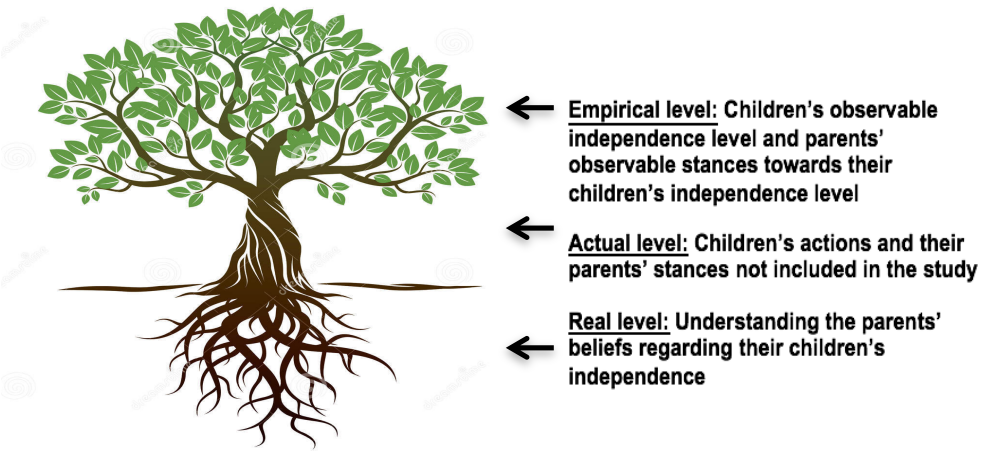


Figure 3.1. Illustration of reality according to the three levels of parental beliefs (Walsh and Evans, 2014).

One of the important features of critical realism is that it contributes to an understanding of the causal mechanism that generates the events that happen at the surface level. If the current study aimed to understand the reasons behind the children's levels of independence and link their parents' beliefs with them, it would help to understand the

causality process. However, this goes beyond the scope of this research. From the ontological perspectives of critical realism, human beings' mental states are 'real' – not in the sense of materiality, but because of their power (Walsh and Evans, 2014). In the current study, it is believed that the parents' beliefs have the ability to produce actions seen at the empirical level; that is, supporting the child in independent self-care skills. Although critical realism does not aim to generalize outcomes, when they occur, generalizations are at the level of probabilistic truth rather than absolute truth (Bisman, 2010); this means the parental beliefs in the current sample can probably be applied to other parents with similar cultures.

When commencing a programme of qualitative research, ontological and epistemological assumptions are among the resources that influence methodological choice (Bisman, 2010, Maxwell, 2012). The current research adopts an interpretive descriptive research strategy, which is explained in the next section.

3.1.2 Study design: interpretive description strategy

The researcher's ontological assumption defines the researcher's view of reality and so guides their methodological decisions (Bisman, 2010, Jackson, 2013). The critical realism framework is appropriate for both qualitative and quantitative methodologies (Maxwell, 2012). In critical realism reality exists, however it is partially accessed to construct knowledge, and this theoretical perspective is aligned with a qualitative

research methodology (Braun and Clarke, 2013). Critical realism stands in the middle ground between naturalistic and scientific (Bisman, 2010). It is qualitative and inductive, allowing the development and clarification of issues and propositions, but also enables a deductive approach (Bisman, 2010). Critical realism understands social perspectives as real phenomena. It holds concepts such as emotions and beliefs as part of reality, arguing that they can cause observable behaviours and actions, rather than abstractions, so that critical realism can work under the umbrella of qualitative research (Maxwell, 2012).

Qualitative research is designed to 'understand how people make sense of their lives and their experiences' (Merriam, 2009, p. 23). Outcomes are therefore expected to provide knowledge about people's thoughts. This makes qualitative research a suitable approach to this study's research question. Research questions and aims determine the most appropriate type of qualitative methodology (Merriam, 2009). A number of qualitative research strategies were examined to see if they would fit the research question. Phenomenology focuses on experience and how it can be transferred to people's consciousness (Husserl, 1970); this research, however, will examine beliefs rather than experience. Grounded theory (Glaser and Strauss, 1967) was ruled out, as this study was not focussed on building theory. Likewise, ethnography was rejected; although the study subjects were Saudi parents and may have been approached from a cultural perspective, it was not an objective to provide thick cultural descriptions (Wolcott,

1999). Additionally cultural sensitivities would make it difficult to conduct methods used commonly in ethnography e.g. observation.

Generic qualitative studies do not follow specific established philosophical assumptions of any of the known methodologies (Caelli et al., 2003). These studies were developed to respond to the need to overcome the restrictions that were established by other methodologies in qualitative research (Kahlke, 2014).The lack of an *a priori* theory in generic qualitative studies makes it essential to clarify the theoretical perspectives that inform the selected methodology (Caelli et al., 2003; Kahlke, 2014).

This research adopted an interpretive descriptive strategy as it aligned with the philosophical underpinning of the applied discipline; it justifies the methods chosen to answer the research question, starting from the data collection tool and sampling, through to data analysis. An interpretive description is developed to provide a qualitative research interpretation with clinical descriptions (Thorne, 1991, Thorne et al., 2004a, Olsen et al., 2013, Thorne et al., 2004c). It is defined by Thorne as “a approach to knowledge generation that straddles the chasm between objective neutrality and abject theorizing, extending a form of understanding that is of practical importance to the applied discipline within the context of their distinctive social mandate” (2016, p. 29).

An interpretive descriptive approach recognises that pure description might not be satisfactory for applied research; rather it seeks understanding of relationships and associations through the

interpretation of data (Thorne, 2016). This corresponds with reality and knowledge within critical realism, where reality is stratified and the aim is to uncover the central level of reality (Benton and Craib, 2001). Interpretive description aims to obtain outcomes that go beyond simple description into more interpretive and deeper understanding, whilst critical realism is also utilised to penetrate the layers of the stratified reality to identify the deeper (*real*) level, the parental beliefs.

The interpretive descriptive approach arose from the demand to find a qualitative approach that provided optimal understanding of complex experiential phenomena, useful in the context of healthcare practice (Thorne, 2016); this corresponds with what I have perceived as a physical therapist and researcher in a rehabilitation clinic. In previous research (Alkhudair and AlEisa, 2014) the applicability of the Pediatric Evaluation of Disability Inventory outcome measurement among normally-developing Saudi children, was investigated using structured interviews. To score a child's caregiver assistance level, the mothers explained their child's independence performance, including their abilities and behaviour, and provided their own feedback about assisting the child while practising functional activities. This research indicated that the mothers' beliefs might play a role in their child's performance and opportunities to develop independence (Alkhudair and AlEisa, 2014). As a paediatric physical therapist rehabilitating disabled children to develop their independence, understanding the beliefs of the parents regarding their children's independence might impact on the

children's rehabilitation. This contributed to the shaping of the research question for the current study.

To generate an interpretive description within the qualitative investigation of clinical phenomena, it is suggested that the researcher should capture certain themes and patterns within their subjective perception. This happens using their epistemological foundation to ground the established methods, and provides systemic reasoning for the field as well as legitimizing the revealed knowledge (Berterö, 2015, Thorne, 1991, Thorne et al., 2004c). Thorne (2016) describes interpretive descriptive strategy as a methodological framework that provides a bridge between theory and practice. She suggests that describing a clinical case qualitatively is not for documentary purposes, but rather takes us a step closer to useful general knowledge. This can be applied in the current research, where the acquired knowledge was collected for theoretical purposes, but provided knowledge that might enrich the children's physical rehabilitation. Interpretive description was used to integrate what was learned from these participants (parental beliefs) with the researcher's reflective clinical reasoning process to provide a deeper understanding, and in the current study to gain an insight into how parental beliefs regarding independence might influence the independence of children with cerebral palsy (Thorne, 2016). Morse (1994) proposes that if the researcher does not provide deep interpretation, the outcome's contribution to knowledge in the domain might be poor. An interpretive descriptive strategy can assist healthcare professionals in their practice, which in turn can help to

make sense of experiences in the healthcare application and possibly clarify a clinical phenomenon that needs to be understood (Hunt, 2009). In the current study, using an interpretive descriptive strategy might help rehabilitation professionals during the rehabilitation of children with cerebral palsy and inform the training and development of their independence.

To provide a framework and logic for the research design, along with the epistemological integrity of the discipline, Thorne (2016) states that an interpretive description is developed to maintain the coherence of the theoretically-driven approach and at the same time provide support for the study design, according to its context and situation. An interpretive descriptive strategy underpins the methods used in the current research, and this is discussed further in the next section.

3.2 The Study Methods

Careful selection of the research method is essential to properly explore the research question. The research methodology and theoretical perspective should influence the choice of research method, in order to achieve congruence between theoretical levels (Carter and Little, 2007, Crotty, 1998). The sampling strategy, data collection, and data analysis employed in this study will be discussed in the light of the philosophical underpinning and research methodology.

3.2.1 Study sites

Participants were recruited from two study sites: the Prince Sultan Rehabilitation Complex (PSRC) and Handicapped Special Care Joud

Centre (HSJC). PSRC is one of the biggest governmental rehabilitation complexes in the eastern province of Saudi Arabia; it operates under the umbrella of the Eastern Province Society of Disabled Persons. The centre was opened in 2002, and caters for children with different levels of disability; its services are comparable to those provided by the Disabled Children Association in the middle and western provinces.

PSRC is one of the 12 governmental rehabilitation centres that are spread over the kingdom to serve 20 main cities. It was chosen for this study because as one of the biggest governmental rehabilitation centres in the province it is expected to serve the largest number of disabled children compared to other centres. PSRC provides medical consultations that involve evaluations and provision of rehabilitation plans for disabled adults and children; these include physical therapy, occupational therapy, speech therapy, psychological services, social services and prosthetic and orthotic units. The centre has outpatient services as well as rehabilitation units. Cerebral palsy constitutes a large percentage of the physical disabled population in Saudi Arabia (Al Salloum et al., 2011b), and many of the disabled children that attend the centre suffer from cerebral palsy. Parents of those children either attend in person with their children or contact the centre administration regularly. Parents of children from two rehabilitation units within PSRC were recruited; the early intervention unit, which cares for children between 3-7 years old, and the day care unit for those aged 7-14. In these units children attend educational classes and are trained in self-

care skills; they also take occupational and physical therapy sessions as part of the rehabilitation programme (PSRC, 2010).

To expand the sample size after preliminary analysis of the pilot interviews (see Section [3.3.6.4]), another study site was used for recruitment. HSJC, is a governmental centre that since 1996 has offered rehabilitation, education, vocational and entertainment services for individuals with special needs within the age from three to 35 years old, It also provides family support and guidance for families of children with special needs (HSJC, 2018)

3.2.2 Sampling strategy

This study adopted purposive sampling (Hansen, 2006, Patton, 2002) as in qualitative research it provides information-rich cases for increased study depth.

Choosing the sample depends on what we want to hear from the participants (Braun and Clarke, 2013). Patton (2002) states that

The logic and power of purposeful sampling lies in selecting information-rich cases for study in depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the inquiry, thus the term “purposeful sampling”’ (2002, p. 46).

Thorne (2016) suggests that purposive sampling is an attempt to identify the group that will provide what seem to be reasonable findings assuming that what is expected is found. Selecting a sample by

applying inclusion criteria guides the research to information-rich participants (Merriam, 2009).

In the current study, sample criteria were derived from the research question. Because Saudi parental beliefs about children with cerebral palsy, and those children's independence are under investigation, two criteria were identified: the age of the child and the degree of disability. Cerebral palsy is generally classified by severity level (mild-moderate-severe) assessed by residual function (Balf and Ingram, 1955, Graham, 2005) (see section [1.4.2.2]); this classification was used in the diagnostic reports of the children in the centre. Development of independence in self-care, mobility and/or social function skills can be expected from children with mild to moderate cerebral palsy, more than from children with severe cerebral palsy.

While the expected age for independence in functional skills is 6.5 years and above, there are no normative data about the expected age at which Saudi children master functional skills (self-care, mobility skills, and social skills). Data from the United States recommends 6.5 years as the lower age threshold for studies of childhood independence (Haley, 1992). It is suggested that children > 6.5 years would have the capabilities to master functional skills and be able to develop independence within their available abilities (see Section [1.4.4]). Parents of children over 14 years old were excluded from the study because they are no longer considered to be children in the Saudi Arabian health sector.

To identify the possibility of cultural influences of parental beliefs, the sample only included Saudi parents (born and raised in Saudi Arabia with Saudi roots ‘Saudi parents and grandparents’), so as to capture the singularity and the impact of Saudi cultural beliefs on child independence, in order to answer the research question in identifying parental beliefs among Saudi parents.

Although the target participants were the children's parents, the entire sample consisted of mothers. As a female researcher it was difficult for me to meet or contact the fathers; in PSRC the female department is separate from the male department and no males are allowed to enter the female area, while HSJC was entirely female centre and men were not allowed to enter. It was possible to meet the fathers in another area of the centre, however the conservative aspects of Saudi culture, particularly gender segregation, were considered to make this difficult, and in addition female administrative staff advised that a female researcher had never met and interviewed fathers before. It was therefore decided not to interview fathers,

This issue has previously been identified in a qualitative study that was conducted in the United Arab Emirates to investigate parental beliefs. The researcher recruited only mothers and suggested it was inappropriate for female researchers to conduct research with men (Crabtree, 2007a).

3.2.3 Sample selection

The sample in this study consisted of mothers of children with mild to moderate cerebral palsy. Those whose children had severe cerebral palsy were excluded from this study; according to the severity of the motor development (Balf and Ingram, 1955), the self mobility of children with severe cerebral palsy is severely limited, even with the use of supporting technology, and these children exhibit few independent qualities (Haley, 1992, Rosenbaum, 2003a, Rosenbaum et al., 2007a). The inclusion criteria were as follows:

1. Saudi mothers;
2. Mothers of children with mild and moderate cerebral palsy according to their diagnosis (using classification of cerebral palsy according to severity (Balf and Ingram, 1955) in the selected rehabilitation centre;
3. Mothers of children aged between 6.5 and 14 years.

3.2.4 Sample size

The sample size was determined by the outcomes of the pilot interviews and what was expected from the research strategy. Initially, ten participants were invited to join the pilot study and interviews were conducted. After preliminary analysis of the transcripts of three of the pilot interviews, it was determined that ten participants was not a sufficient quantity to optimally address the research question, and the quality of the provided data required improvement. It was decided to discard the original interviews and recruit further participants (see Section [3.3.6.4]). There are no rules for sample sizes in qualitative

research (Patton, 2002), and a lack of clarity in the arguments concerning them (Mason, 2010). This section will describe how this study's sample size was decided.

Malterud et al. (2015), recommend 'information power' to guide the sample size; the more information power the sample holds, the lower the sample size. Malterud determined five items that impact the information power of the sample. First, the aim of the study: a broad study aim requires a larger sample size than a narrow aim in order to obtain sufficient information. The aim of the current study specified *Saudi* parental *beliefs* regarding *independence* of children with *mild to moderate cerebral palsy*, a narrow study aim that required a smaller sample size. According to Malterud, et al. (2015) studies with a limited theoretical perspective usually require a large sample size in order to provide sufficient information power. In the current study the methodology and theoretical perspective were clearly identified (see Sections [3.2.2 and 3.2.1]), allowing for a smaller sample size. The quality of dialogue also controls the need to expand the sample size; if the dialogue is strong and clear, a smaller sample size is needed, and vice versa. Malterud, et al. (2015), believe that this is influenced by the personality of the participants and their ability to express themselves. According to Thorne (2016), six participants is a small sample size, while Braun and Clarke (2013) believe that 15 to 30 interviews are sufficient to identify patterns across the data. In this study it was anticipated that up to 20 participants would be needed; also it was intended to interview them twice for greater data richness and depth

Malterud et al. (2015) recommend starting with an initial sample number, which will be evaluated and changed during the research process. Onwuegbuzie and Leech (2007) suggest that sample size should correspond with that of studies employing the same methodology. The majority of studies (Cunningham and Jillings, 2006, Barrett and Randle, 2008, Gray et al., 2014, Thorne et al., 2004b) using an interpretive descriptive strategy had a relatively small sample (five to 30 participants). In the current study, the upper limit was anticipated to be 20 participants. Nineteen mothers agreed to participate and were recruited for interviewing (15 participants from PSRC and four from HSJC) and 12 mothers were interviewed twice, so 31 interviews were obtained in total.

3.2.5 Sample recruitment

At the beginning of the data collection period, the coordinator (responsible for training and research in PSRC) was contacted to transfer papers to the ethics committee and to facilitate contact with the different departments. After obtaining ethics approval from the PSRC ethics committee, which took around two months (Appendix 1), the coordinator contacted two departments: the intervention (preschool) (3-7 years) and (day care) school age (7-14 years) to prepare the list of parents who fitted the study's inclusion criteria.

Centre administrators were provided with the inclusion criteria and identified potential children whose parents might be suitable for the study. Participation invitation letters were sent home to the mothers in the children's bags. However, the initial response rate was very low;

only two mothers out of twenty-six replied via phone to say that they were willing to participate. Centre administrators in both the preschool and school age departments therefore proposed contacting the mothers who met the criteria directly by phone to ask if they would participate in the study: 10 mothers agreed and participated in pilot interviews at the centre

3.2.6 Data collection

This study utilised qualitative semi-structured interviews. In this section the data collection method will be described including the pilot interviews.

3.2.6.1 Semi-structured interviews

When the researcher aims to collect a special kind of information about meanings and understanding constructed by people regarding their experiences, it is suggested that the primary choice for data gathering should be interviews (Grbich, 1998, Merriam, 2009).

Interviews are conducted to discover things that are difficult to observe, such as feelings, thoughts, beliefs, or behaviours that might have happened previously. They also allow us to try to understand how people interpret the world around them (Merriam, 2009; Patton, 2002). Interviews are suggested to be appropriate to use with experience-type research questions, providing rich detail when exploring the understanding, perceptions, and constructions that people hold about a topic (Braun and Clarke, 2013). Interviews are also chosen when seeking depth and complexity in data (Mason, 2002).

According to the relativist epistemological position held by the current study, a meaningful way to generate knowledge and access this information is through interactively talking to the mothers. Asking them questions, and listening to their answers provides access to their parental beliefs, knowledge, views, and understanding, which reflect the deepest layer of social reality (*real level*), and this is what the current research explored (Mason, 2002; Maxwell, 2012). It was considered that unstructured interviews characterised by open-ended questions without following an interview guide might lack focus, whilst structured interviewing with rigid questions might not allow access to the participants' perspectives and understanding of their beliefs. Both interviewing structures (structural and unstructured) were considered unsuited to providing knowledge regarding the parental beliefs (Merriam, 2009). Semi-structured interviews allowed the building of rapport, listening to the interviewees, allowing pauses and building the interviewer-interviewee relationship, which was helpful in fostering trust between the researcher and the mothers in preparation for the second interview (Merriam, 2009, Thorne, 2016).

In January 2015, 10 interviews were conducted and analysed, with critique from PhD supervisors to evaluate the conduct, efficacy and the preliminary analysis of the interviews. These were considered pilot interviews, and their preliminary analysis was used to inform the development of the interview guide and the sample size.

One of the initial pilot interviews was included in the sample; the others were discarded. Two of the pilot interviewees were re-interviewed and included in the first round of interviews.

Mothers were given a choice of interview locations, either their houses, public cafes, or inside the centre; all of them chose the recruiting rehabilitation centre. They were provided with a comfortable sofa, and Arabic coffee with dates was offered; this is usually expected when hosting in Saudi society to create a warm and comfortable environment (Braun and Clarke, 2013). Each mother was given a further copy of the information sheet (Appendix 2), alongside a verbal explanation of the research aim and the nature of the data that would be collected. They were given the chance to answer questions. Confirmation of confidentiality was offered, and they were informed that the interview would be audio recorded, that they had the choice to withdraw from the study at any time without giving a reason, and that their child's care would not be affected. Afterwards, the participants formally agreed to join the study by signing the consent form (Appendix 3).

An interview guide (Appendix 4) was developed from the literature review, the aim of the research and the researcher's experience. This was used to guide the interview, with prompts used where required, and participants given opportunities to discuss what they thought was relevant to the phenomenon under investigation.

Participants were given sufficient time at the beginning to talk about their experiences and their feelings when they first found out about their

children's disabilities, and talked about their social or financial circumstances, then about their children's abilities and their training plans to improve their children's functional abilities and independence. The interviews were tape-recorded and took 50-90 minutes.

Data were analysed every two or three interviews; any new themes or areas that needed more exploration were highlighted in order to develop new questions. The first interview rounds ended in November 2015, and the data was analysed and used to develop the second round interview guide.

Two rounds of interviews were conducted as it was believed that this would facilitate the development of rapport, allow deeper probing into areas of interest and unexplored areas to be approached, and increase the potential credibility of interpretively understanding the obtained results regarding mothers' beliefs (Thorne, 2016).

All the participants of the first round interviews were invited to the second round interviews, however only twelve mothers were able to participate in the second round interview, nine recruited from PSRC and three from HSJC. In the second interview the mothers usually have to provide contextual information, as this had been discussed previously. The mothers appeared more comfortable in answering the second interview questions readily. The interview guide for the second interview was built on the analysis of the first interviews (Appendix 5), allowing the mothers to expand their responses to topics that they might have previously only discussed briefly, allowing greater depth of investigation

to take place (Hansen, 2006, Knox and Burkard, 2009). The second round of interviews lasted until the end of April 2016.

After each interview I took notes about my perception of the interview, the mother and how themes might be raised. For example, in her interviews M3 frequently repeated expressions about God's will and her strong religious beliefs, that I thought deserved to be documented in the field note; this motivated me in the next interview to encourage the mothers to speak more about this area. It also helped whilst analysing this mother's transcript and provided first order interpretation of the obtained data.

In another example, when M13 talked about training her child, the subject of ownership of her possessions (clothes, chair, bed etc.) arose. She said: '*Because it's her right; she has rights, it's not because she is in a wheelchair that she has no rights*'. After analysing her interview a question about beliefs regarding children's rights was developed.

After the second round of interviews had finished, analysis of all the data from both interview rounds was continued. Figure 3.2 below summarises the data collection process.

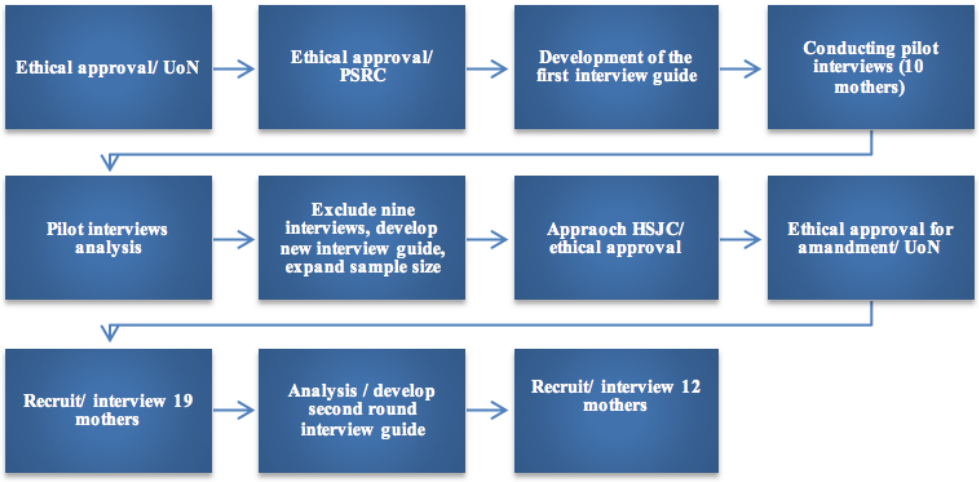


Figure 3.2. Summary of the data collection process.

3.2.6.2 Interview transcription

Transcriptions were conducted after each interview in Saudi Arabic by the researcher and were then translated into English by a local transcription service. Transcripts were translated to English, and interviews of M3, M6, and M13 were back-translated into Arabic to ensure quality of translation. English translation interviews were provided to the research supervisors to be able to provide a robust process in ensuring interview quality and the opportunity to discuss subsequent analysis. Confirmation of robustness of the interview was given after nine interviews that were part of the study.

Analysis was undertaken on the original transcripts alongside listening to the verbatim interview recording to account for the vernacular Arabic accents and gestures. Within the sample, there were four different Saudi Arabian accents, and written transcriptions were sometimes

unclear due to incomplete sentences, usually based on popular sentence structures. This therefore provided a higher level of communication with the data than reading the written transcripts alone (King and Horrocks, 2010).

3.2.6.3 Interview guide

An interview guide is developed for use in semi-structured interviews to help the interviewer remember the main topics, and to ensure topics of interest are covered (Hansen, 2006). However, there is flexibility about how the questions are articulated (Hansen, 2006; King and Horrocks, 2010; Merriam, 2009). King and Horrocks (2010) suggest that the development of the interview guide should depend on the researcher's personal experience, the research literature and the outcome of the preliminary work. In the initial interview guide (Appendix 6), my experience as a physical therapist, with a background in the research of outcome measures that examined child independence and experience on how to develop independence for children with cerebral palsy influenced the selection of topics. It focused on asking directly and specifically about the child's skills and his or her level of independence. Moreover, selection of the child's skills was derived from literature (Haley, 1992) that detailed the functional skills domain (self-care, mobility and social functions) and their relation to the child's development towards independence. The first interview guide included direct questions about these skills, about the child's ability to eat, dress, or take a bath, or the level of their ability to move and transfer – either

they crawl, or walk with assistance – and the mother's beliefs regarding the child's abilities and chances to develop. For example:

> *Researcher: 'She can walk?'*
>
> *Mother: 'She used to walk two years ago, but not any more.'*
>
> *Researcher: 'Before, when she was younger, she used to walk?'*
>
> *Mother: 'Yes she could walk and talk and go to the toilet on her own, but now God's glory, this is what God wants, the girl relapsed, not moving and not talking.*'

This extract shows how the interview, according to the initial interview guide, focused on questions regarding the child's ability to practice a skill (in this case walking). The closed questions about skill mastery provided answers that lacked depth and might have transferred judgemental feelings in cases where the child had not mastered the skill under discussion.

A modified interview guide (Appendix 4) was developed using the preliminary analysis of the conduct and content of the pilot interviews. Changing the research guide is an advisable step during data collection in qualitative research, according to King and Horrocks (2010). During the pilot interviews the mothers brought up things that were not expected and therefore were not mentioned in the interview guide. Continuous preliminary analysis of the data helps researchers to be responsive and add any emerging themes (Merriam, 2009). For

example, one of the mothers (the mother of the second interview) of the pilot study talked about the father's feedback concerning her child's refusal of toilet training:

> *Mother: 'When she comes from school I remove the diaper but she starts to cry and then he [the father] asks me to return the diaper and make her quiet.'*
>
> *Researcher: 'You used to do this regularly?'*
>
> *Mother: 'Yes; every day I take the diaper off and he returns it – he doesn't want noise and he said leave it, no need to make her learn toileting.'*
>
> *Researcher: 'Is it because he doesn't want noise, or he thinks she is still little?'*
>
> *Mother: 'Both; he doesn't like noise and he believes she is still little, and he said you are putting in a lot of effort, just relax.'*

In this example, there was recognition of the father's role in training the child with the necessary skills to be independent, which makes it a question in the modified interview guide. It also demonstrated the importance of interviewing skills; for example, in the last example there was a guiding question where the response appeared to be restricted to the constraints of the question: '*Is it because he doesn't want noise or he thinks she is still little?'* then the mother replied*: 'Both; he doesn't like*

noise and he believes she is still little, and he said you are putting in a lot of effort, just relax'.

The modified interview guide for the first interview round focused on talking about general areas around the child's abilities and current training, how these related to the child's potential to be independent, the mother's understanding of independence, and how she believed the child's surroundings influenced her role in developing it (Appendix 4). For example, instead of asking the mother a direct question such as: 'is your child able to walk or crawl?' or 'if your child is able to walk why do you think you carry him/her?', there were adapted questions that aimed to explore the mothers beliefs more effectively. An example is: 'is there any difference in your child's performance in toileting/walking in school and at home? Why do you think there is a difference?' This type of question opened up discussion about whether the child performed differently and was more independent in the school, and what the mother's thoughts were regarding this.

To develop the second round interview guide, preliminary analysis was applied to the data (interview transcripts and field notes) from the first-round interviews, and the themes that emerged informed the second-round interview guide (Appendix 5). Questions from the research diary (field notes) were also used to develop the interview guide. I took this field note after interviewing M14:

> *The mother brought to my attention that she is having some kind of pampering or what can be called psychological protection for*

her daughter, although she was talking of the child's anger, she was overwhelmed by what she believed to be developments in her personality and that she is responding to her'

This excerpt from the field notes supports the focus on the child's personality development in the second round interview, raising a question about linking the development of the child's personality and independence development.

The interview guide for the second round interviews was initially categorised according to the emergent themes including: child psychology, factors influencing independence, mother's beliefs, maternal behaviour, maternal childrearing beliefs, maternal health beliefs, mother's feelings, religious and cultural beliefs (Appendix 5). It included a large number of questions, and subtitles were created to classify primary and secondary questions according to their importance. More questions were formed, relating to the mother's thoughts about the child's role in their own independence development, and further exploring how the mother understands her child's independence and what she expects from the child now and in the future. An example of the major topics are: mother's response regarding her child's attempt to be independent, her beliefs regarding child responsibility, her thoughts regarding improvement impacting on her and her child, siblings' roles, strategy in training skills (together or separate), and how mothers link their children's cases with their faith.

There were also individualised questions to be asked according to what was recorded in the reflexive notes regarding each participant. For example M12 talked in the first interview about her child's fear and linked it with her child's level of understanding; a question was developed asking if, and how, she thought that this fear has any relationship to her child's development of independence.

3.2.6.4 Pilot Interview Process

Pilot interviews were conducted to examine the researcher's interviewing skills, and as part of the learning process in interview technique and structure. The pilot study also helped to identify the appropriate sample size through preliminary analysis of the interview transcripts.

Ten mothers were initially recruited. As soon as the first interview was conducted it was transcribed and translated (see Section [3.3.6.2]); the transcription demonstrated an unsatisfactory level of data quality according to the supervisors' critique. The mother's answers were simple and short, and the discussion contained sequential questions and answers without any explanation of what the mother thought and felt. The researcher's inadequate interviewing skills and misunderstanding of the meaning of 'data depth' did not guide the interview sufficiently to provide adequate explanations of the phenomena being explored.

A short example from the first pilot interview demonstrates the problems:

Researcher: 'I want from you details about what you do with him, starting from the morning; when he wakes up do you take him to the toilet or does he go alone?'

Mother: 'I take him.'

Researcher: 'Is he able to go alone?'

Mother: 'No because of walking'.

Researcher: 'Can he go with the walker?'

Mother: 'He is asking me to go with the walker.'

Researcher: 'Do you allow him?'

Mother: 'It is difficult, I have to go with him.'

Researcher: 'Is he able?'

Mother: 'He walks to the toilet with me holding him.'

Researcher: 'Are you avoiding using the walker?'

Mother: 'The walker is not close most of the time, and he wears a diaper and I have to take him to the toilet and clean him.'

Further interviews were conducted and translated transcriptions were sent to them for comments. Having reviewed the interview transcription, further feedback was given to improve my interviewing skills. While conducting these interviews one supervisor offered to do a mock interview to facilitate direct comments and highlight the areas, which could be improved. Although the interviewing skills were improved,

further interviews failed to adequately address the research question. A new interview guide was developed which improved the quality of the outcome data and provided more depth to the dialogue.

3.2.7 Data Analysis

Qualitative data analysis is a process that transforms data obtained from interviews or field notes into results, making sense of the data in the light of the research question. The researcher combines, condenses, and interprets the data to obtain its meaning (Merriam, 2009). Data analysis approaches are utilised to filter qualitative data and reflect the underpinning assumptions about what is important and can be obtained from the data (Hansen, 2006).

In the current study, data analysis was conducted simultaneously with the interviewing and note taking, and continued throughout data collection (Pope and Mays, 2002).

In light of the interpretive description strategy, an iterative interpretive thematic analysis was adopted (Thorne, 2016). Interpretive analysis aims to go beyond descriptive analysis, seeking a deeper level of understanding and meaning. Instead of asking what is interesting in the data, it also asks why it is so (Braun and Clarke, 2013). The following section details how iterative thematic analysis was applied in the current research.

3.2.7.1 Iterative interpretive analysis

The iterative interpretive thematic process moves between analysis and collecting data and then back to analysis. It reflects on the collected

data, and the identified patterns and themes are then used to re-focus the interview guide, engaging the researcher in an intellectual process that is the base of qualitative research (Hansen, 2006; Thorne, 2016; Thorne et al., 2004). This intellectual process engages in a discussion between theory and data, avoiding theoretical hypothesizing and theory-based descriptions, and rather providing rich interpretation in light of the current research's theoretical perspective (Thorne et al., 2004c).

To produce good qualitative data analysis, it is suggested that the researcher should follow 'analytic sensibility'; this allows the researcher to read and interpret the data through an analytic lens, where the analysis moves from initial descriptive beginnings to become more interpretive (Braun and Clarke, 2013). Data analysis in the current research involved data immersion, where the researcher became closer to the data by listening to the audio files; transcribing as well as reading the transcriptions improved familiarity. This included becoming sensitive to the process of interviewing and responding to the emerging data in order to help provide a connection between different aspects of the data (Hansen, 2006, Thorne, 2016).

In personal correspondence, Professor Sally Thorne stated: 'The interpretive descriptive strategy does not provide explicit requirements that must be followed precisely, but rather encourages scholars to reflect on what analytic steps will make the best sense' (personal communication, March 4, 2016). She recommended following data analysis with a set of sequential steps to make sense of what was being

seen in the data, especially since I was new to qualitative data analysis. To address this, the steps of data analysis were adapted from Braun and Clarke (2013), Braun and Clarke (2006) and King and Horrocks (2010). In the current study, the data analysis stages started with familiarisation of the transcripts, as the interviews were transcribed immediately. Codes were created inductively, whereby they emerged during data collection. Although preliminary analysis was applied during the on-going data collection, these emerging themes were used to raise further questions, rather than deductively analyse the new data.

Morse (1994) proposed that interpretive description requires a cognitive process that is highly conceptual and facilitates awareness of the important elements of the research data. It necessitates a conceptual structure that effectively interprets the data, providing knowledge that reflects the phenomena (Thorne, 2016). This process was employed in the current research. It started with *comprehending* where the researcher passively absorbed without making judgments. It began simultaneously with data collection, and continued throughout the process of data analysis, including coding and making notes; this allowed the generation of new questions that could penetrate to a deeper layer of the phenomena and provide more understanding.

The second step was *synthesising,* where (relevant) data, reflecting the research question, was distinguished from the (irrelevant) data, which did not. In the current study, this occurred at data analysis during and after the data collection had finished, and included the coding process and the placing of the codes into descriptive and then interpretive

categories. After grouping the interpretive codes into interpretive themes, these were discussed with the supervisors in light of the research question. This process was applied during data collection, where most of the questions were developed to provide data related to the research question; some of the data (more relevant) was closely linked to the mothers' beliefs (e.g. the mother's understanding of independence), while other data (poorly relevant) was evaluated as poorly linked (e.g. the mother's feelings and behaviour). Some of the data for example the mothers' experience when they first found out about their child's disability was evaluated as not providing knowledge about maternal beliefs and was therefore considered irrelevant. This stage acted as a data filter, selecting, revising, verifying and speculating about various elements. Subsequently, the relevant data that reflected 'the best guesses' and addressed the research question were identified in the *theorising* stage, where the data was interpreted and linked with other theoretical and empirical sources. The interpretive themes reflecting the maternal beliefs regarding their children's potential and training, and the religious and cultural beliefs and factors informing and influencing these beliefs were interpreted in depth and linked with the related literature. The final step of Morse's process is *recontextualising* (Morse, 1994). At this step the synthesised data collection and analysis was articulated in an outline that made it applicable in other contexts.

This process helped to generate knowledge by making the theoretical concepts practical, helping in understanding how the eventual findings would be shaped by rigorous conceptual work (Thorne, 2016). This

process of data analysis aligns with the perspective offered by Thorne (2016) whereby the researcher, not the procedure of data analysis influences the interpretive process, following iterative not sequential reasoning. The stages of the cognitive process and the corresponding stages of the current research are illustrated in the following table, 3.1.

Stage in cognitive process	**Process in the current research**
Comprehending	• Preliminary analysis of the pilot interviews; • Developing new interview guide; • Preliminary analysis during data collection; • Developing new questions from the emerged themes for deeper knowledge.
Synthesising	• Data analysis for the whole body of data into descriptive, then interpretive codes; • Filter the revealed data highlighting the (relevant) data and excluding (irrelevant) data.
Theorising	• Deep analysis and interpretation of the (relevant) data, linking with literature.
Recontextualising	• Implication of the newly generated knowledge by making the theoretical concepts practical.

Table 3.1. Stages of the cognitive process.

The taxonomy in which the findings are presented has been classified as ‘topical survey’, ‘thematic summary’, ‘thematic description’, and ‘interpretive explanation’ according to Sandelowski and Barroso (2003).

This classification helps in keeping a distance between levels of abstract analysis and the interpretation of data, it also provides knowledge of what the possible outcomes of the study will look like. Thorne (2016) believes that this space lies between 'thematic summary' and 'conceptual or thematic description', which reflects themes and concepts that interpretively integrate portions of data. However, the current study's scope moves beyond obtaining interpretive meanings of themes into further explanation, and this is classified as 'interpretive explanation'. Findings in this category emphasise various explanations of interpretive meanings through a single thesis (Sandelowski and Barroso, 2003).

3.2.7.2 The coding process

Although Thorne (2016) advised early coding to be broad-based, I found it essential to undertake detailed coding during analysis. The study intended to identify maternal parental beliefs, and therefore the data included statements about feelings, understanding, behaviours, thoughts, and opinions, which were interpreted as relevant to understanding the mothers' beliefs; detailed coding appeared necessary to deliver more information about these beliefs.

The preliminary analysis of the first round of interviews provided codes, the most frequent of which were used to develop the second round interview guide (Appendix 5). These codes were grouped into themes that were derived mostly from the literature. The following table, 3.2, presents these codes and the corresponding themes.

Theme	Code
Child psychology	Child fear; Child psychology motive: independence; Child weak personality and self-esteem.
Factors influencing independence	Encourage independence to reduce commitment; House structure as independence barrier; Parents perceive their child's stubbornness; Siblings encourage independence; Surrounding experiences.
Mother's Beliefs	Belief in parental role; Mother recognizes her child's real abilities; Mother's understanding of independence.
Mother's behaviour	Mother facilitates independence.
Maternal child rearing beliefs	Mother-child special attachment; Child's responsibility regarding independence; Mother encourages child social interaction; Mother justifies/ does not justify (anger/ fear/ jealousy/ aggressiveness).
Maternal health belief	Adapting professional opinions; Understanding and independence; Health and physical abilities make barrier; Mother classifies her child's health status; Physical or cognitive limitation as a child isolation cause; Professional skills belief.

Mother's psychology	Child improvement enhances mother's hope; Child improves above expected levels; Mother surrenders.
Religious and cultural belief	Religious beliefs; Cultural beliefs.

Table 3.2. Codes and themes from analysis of the first round interviews. After completing data collection, analysis was carried out on the whole body of data.

In the early versions of data coding, there was no coherence between codes in term of the level of interpretation, which resulted mostly in interpretive codes with fewer descriptive codes. For instance, in the same stage of coding process this group of codes that revealed from analysis of M13's interview – child isolation, task mastering, child with special needs, child understanding, doctor's opinion, child's speech, professional skills, and child's health and physical status – appeared to be interpretive codes. Also at the same stage of the coding process, some interview coding revealed a mix of descriptive and interpretive codes, as is revealed in the following example of coding from M6's interview: child treated like normal, mother knows child's abilities, speech issues, child concentration, child improves in skills. Codes like 'child treated like normal' are more descriptive, while 'child concentration' is more interpretive. At this stage it was recognised that coding in this manner with poor coherence might have interfered with the possibility of obtaining clear sequencing of the development of the

themes, which may in turn have caused a failure to justify the revealed themes as truly reflecting the data. Therefore coding of the data for the first twenty interviews was repeated, starting with more descriptive codes, and followed by grouping into interpretive codes: this step was also recommended by the supervisors during their continuous evaluation of the data analysis processes in order to gain rigor and transferability of the data analysis process. Therefore, to improve my skills in coding and for more understanding of the coding process more reading was performed.

The coding process in the current study followed the guidelines of King and Horrocks (2010) in basic system thematic analysis, where descriptive coding occurs during the *first stage*. They recommend that *descriptive codes* should be relatively close to the data and represented as single words or short phrases. To achieve a dispersive level, in vivo coding was applied to the data with descriptive codes. In vivo coding is recommended for new researchers, as it uses participants' language to create early labels. This is beneficial to information retrieval as it can be a tool for conceptualising related ideas into coherent patterns (Miles et al., 2014, Pope and Mays, 2002, Thorne, 2016, Thorne et al., 2004c).

After finishing all of the data coding, the codes were reviewed (most of them twice) to confirm the descriptive level. An example of how data was put into descriptive codes as a first stage is presented in Table 3.3.

Mother's quote	Descriptive code
Yes, he isn't accustomed to, and he is lazy. When he wants something, he goes inside my room and takes it, e.g. he goes inside my room to take his daily allowance; he opens the drawer and takes his allowance.	*He is lazy;* *When he wants something, he gets it.*
I considered improving his condition, if God wills, and he will be like normal people with time. I also thought about taking care of his education along with his father. We could cooperate, and if God wills, he will improve.	*If God wills;* *Take care of education;* *He will improve.*

Table 3.3. Example of descriptive codes.

After reviewing all codes at the descriptive level, *stage two* consisted of *interpretive coding*, where interpretation of the meaning is desired. Descriptive codes were grouped into interpretive codes that reflected their meanings (King and Horrocks, 2010). While creating interpretive codes from descriptive codes, frequent visits to the data were needed to keep them in context. The creation of interpretive codes was influenced by the research question and the disciplinary approach (King and Horrocks, 2010). Table 3.4 illustrates how grouping descriptive codes developed interpretive codes.

Descriptive codes	Interpretive codes
• Want to reduce burden on me; • Bored from dressing him; • Don't want to put a load on people to take care of him; • Not to be a burden on brothers in future.	Avoid being a burden
• Am afraid he will fall down; • Afraid someone will hit him; • Can't leave him alone because he loves danger; • Hide sharp things.	Protection
• God's will above everything; • I believe this is God's will; • If God wills, she will understand; • Accepting what God writes for me.	Rely on God's will

Table 3.4 interpretive codes derived from grouping descriptive codes.

The interpretive codes were revised several times and codes with similar meanings were merged, for instant, 'close family support', 'negative influence from surrounding environment', and 'surrounding over protecting the child' were merged to form the code 'extended family'. The interpretive code list was gradually reduced; in every version of the list there were comments on which codes could be merged, with an explanation. These versions were then arranged in a folder to produce an audit trail of how the interpretive codes and themes were developed. The major stages of developing and organising the themes were also documented, in order to demonstrate the process of their development; auditability is a criterion that is recommended to ensure quality in qualitative research (King and Horrocks, 2010, Thorne

et al., 2004c, Tracy, 2010). The interpretive code labels were then reviewed to achieve a more abstract level. After finalising the interpretive stage, the *final stage* was to create the *overarching themes*, so that the interpretive codes could be put into larger groups under themes that reflected a higher level of abstraction. The interpreted codes were accordingly suggested to be grouped either into the *ladder of engagement* or the *mother's understanding of independence*. Arguing that as a physical therapist the key word in the research question is independence, and therefore, the theme should be related to it, the two overarching themes were clearly proposed, which made the interpretive codes within them easy to understand. This is demonstrated in Appendix 7.

I believe that the overarching themes address the research question. In the current study, maternal beliefs regarding the independence of children with cerebral palsy were investigated, explored, and interpreted. An analytical lens reflecting the discipline was applied in order to distinguish the relevant data (Thorne, 2016). As a physical therapist, I searched for understanding of maternal beliefs regarding independence to introduce the subject to the physical therapy community and to contribute to the body of knowledge of the physical therapy literature. The overarching themes, using labels related to child independence, were believed to be close to the concerns and interests of the physiotherapy community, and it was believed that a different display of codes would provide a different story (Thorne, 2016). The

grouping of the overarching themes according to the *mother's beliefs of independence* was believed to best address the research question.

3.2.8 Ethical considerations

Ethical considerations associated with research are usually enacted to protect the participants from harm during the research process (Hansen, 2006). Ethical procedures usually start with procedural ethics, that is, the ethical permission obtained from the organisation or institutes (Tracy, 2010). Usually in qualitative research, there is no danger of physical harm, but emotional distress is a possibility (Silverman, 2011). This section will explain the ethical considerations that were followed in the current research, including confidentiality, anonymity, and informed consent.

3.2.8.1 Participant confidentiality and anonymity

Data were protected by securing it in a locked office on a password-protected laptop. Participant anonymity was achieved by using pseudonyms so that their identity could not be identified through the research results, a table to unlock these pseudonyms was available during data analysis to insure the matching of information. Attention was especially paid to the recorded audio files, which were kept secured, and only the researcher was allowed to listen to them. In qualitative research, the relationship between the researcher and participant is complex, and the method is interactive. This means that the researcher rarely works with anonymous data, because the identity of the participant is already known to the researcher (Hansen, 2006). However, when some transcripts were sent to the translator, and also

while writing the research report, all of the children were given pseudonyms to ensure anonymity, while a schedule of corresponding real names was kept secure (King and Horrocks, 2010). Moreover, during the interviews the mothers provided some information that was not related to the research question, for example their experience when they first found out about their child's condition. It was important to give the mothers the chance to express their feelings in order to show respect for their emotions. However it was recognised that as long as these data did not address the research question they should be kept confidential and not be included in the writing up.

3.2.8.2 Procedural ethics:

In the current study, ethics approval from the University of Nottingham's Medical School Ethics Committee (Ethics reference No. OVSb14082014 SoHS PhD), PSRC and HSJC were obtained (Appendices 1 and 8). In this ethical agreements, the university and research sites made sure that there were sufficient precautions to prevent any harm that might be caused during the research process. An amendment (capturing the second study site) was sought due to changes in the data collection process. The interviews were conducted by the primary researcher with the children's mothers, and there was no need for any support from the centre, so children's care and staff capacity were not affected while the study was being conducted.

3.2.8.3 Informed consent

Although the participants had read the invitation before coming to the interview, the details of the research were explained to them to ensure that they fully understood before they signed the informed consent form (Appendix 3). The informed consent process involved provision of an information sheet that explained the possible risks, what would happen to the data, and information about confidentiality. It also included an agreement to participate stating that participation was voluntary, with clarification that it was possible to withdraw at anytime without giving a reason (Hansen, 2006). It is also worth mentioning that the researcher had no previous connection to any of the participants, so consent was not influenced by any party interest or emotional commitment. It was also recognized that consent was ongoing and not a one-off conversation (King and Horrocks, 2010), this was especially important as the research had two rounds of interviews, and continued allowance for the participants to withdraw was essential.

3.2.8.4 Situational ethics

Participants were informed that there might be an exception of confidentiality if something reportable or of concern was revealed during the interview. In this case, the parent would be invited for a private conversation after the interview with the researcher and the person in charge at the research site, and if necessary the appropriate authorities would be communicated to, according to the nature of the concern (social care, health care, etc.).

One of the challenges I faced as the researcher was the expectation of emotional distress, because the interviews had the potential to elucidate a complex mix of feelings, thoughts about the future, and opinions. During the mothers' explanations, especially when comparing their child's abilities with their other children, or discussing their thoughts about their children's future, emotionally distressing moments occurred. This was usually either because of compassion toward the child, or worries about the child's future if the mother and child became separated for any reason, such as the mother dying. However, this was overcome through emotional containment, showing understanding and respect for the mother's feelings, and giving the mother the option to stop the interview, or continue it later if she preferred. There was also the option to arrange a meeting with a psychiatrist if the mother felt she needed it, and this was also mentioned on the participant information sheet. The second challenge I faced was to be careful not to provide an opinion on the mother's routine in training the child or in dealing with his or her condition. In order to avoid judgmental impressions, I spoke less and allowed the mother to take her time explaining, and if the mother asked questions about the child's training I referred her to the physical therapist of the centre to discuss it.

Children with severe cerebral palsy can have very poor independence, so to prevent psychological pressure on their mothers they were excluded during sample recruitment.

3.3 Conclusion

This chapter began with a discussion of the theoretical perspectives (critical realism) that underpin the research, demonstrating how the research ontology and epistemology were recognised. The research methodology (interpretive descriptive strategy) was outlined and related to the research question showing its congruence with the philosophical underpinning.

In the research method section, the research process was detailed, illustrating its stages in line with the research methodology. The theoretical position and epistemology were also clarified. The ways that the pilot interviews influenced the sample size decision and supported the development of the interview guide were examined. A discussion of the coding process looked at the stages and the overarching themes that reflect the research question. In the next chapter the findings will be presented.

4 Chapter 4. Findings: Study participants

This chapter describes the study participants and demonstrates the relationship between the identified themes. It will be divided into three sections:

- Section One will provide information relating to the study participants and their participation in the interview process;
- Section Two will provide an overview of the findings of the current study, by describing the major four themes: 'religious and cultural beliefs', 'beliefs in their child's potential for independence', 'beliefs in their child's training towards independence', and 'factors that influence belief development'. This section will also examine relationships between the four themes;
- Section Three elaborate the relationship between the maternal religious an cultural beliefs and the other mothers' beliefs, in order to clarify how it is founded that informed the maternal beliefs regarding child potential and training to be independent.

4.1 Study participants

19 mothers participated in the study, sharing their beliefs regarding their children with cerebral palsy. The children of these mothers comprised six girls and 13 boys, with ages ranging from six to 13 years; 10 children were diagnosed as having mild cerebral palsy and nine with moderate cerebral palsy. Of the 19 mothers who took part in the first

round of interviews 12 also participated in the second round. The first and second round interviews were conducted between January 2015 and April 2016. Non-participation in the second round of interviews was generally as a result of either a move to another city (three mothers), pregnancy, or inability to travel to the interviews (Table 4.1).

Participant	Gender of child	Age of child	Birth order	Cerebral Palsy severity	Participated in both interviews	Reason for not participating in second interview
M1	M	9 y	First	Mild	Yes	
M2	M	7 y	Fourth	Moderate	Yes	
M3	F	9 y	Fourth	Moderate	Yes	
M4	F	9 y	Second	Mild	Yes	
M5	M	8 y	First	Moderate	No	Health status/ pregnant + transportation issues
M6	M	7 y	First	Mild	Yes	
M7	M	8 y	First	Mild	Yes	
M8	M	9 y	First	Mild	Yes	
M9	M	7 y	First	Mild	No	Moved to another city
M10	M	6 y	Second	Mild	Yes	
M11	M	13 y	First	Moderate	Yes	
M12	M	6 y	First	Mild	Yes	
M13	F	7 y	Fourth	Moderate	Yes	

M14	F	7 y	First	Mild	No	Health status/ pregnant
M15	F	7 y	Second	Moderate	Yes	
M16	F	6 y	Fourth	Mild	No	Moved to another city
M17	M	7 y	First	Mild	No	Busy
M18	M	8 y	First	Mild	No	Moved to another city
M19	M	10 y	First	Moderate	No	Transportation issues

Table 4.1. Description of the children of participating mothers.

4.2 Maternal beliefs regarding the independence of children with cerebral palsy

Analysis of the data revealed that the mothers expressed their beliefs regarding their children's independence in terms of the children's potential to be independent and how to train them to gain independence. The data also showed that there were several factors that might have contributed to the development of these maternal beliefs, with maternal religious and cultural beliefs being an overarching theme.

Maternal beliefs were represented within the following interpretive themes:

- ‘Maternal religious and cultural beliefs’;
- ‘Maternal beliefs in child’s potential for independence’;
- ‘Maternal beliefs in child’s training toward independence’;
- ‘Factors that influence belief development’;

These four themes are illustrated in Figure 4.1 below.

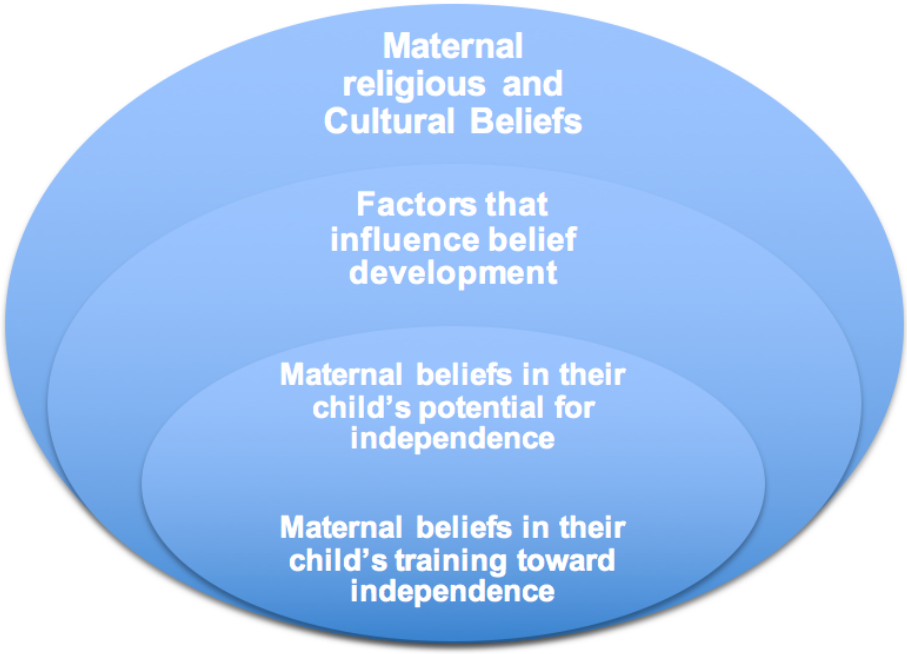


Figure 4.1 Maternal beliefs regarding independence of children with cerebral palsy.

Figure 4.1 was designed to illustrate how the revealed themes can reflect the maternal beliefs regarding independence and how they relate to each other. It was found that the mothers’ beliefs about their children’s potential and training could provide an immediate understanding of their beliefs regarding independence. This explains why both themes. ‘Maternal beliefs in their child’s potential for independence’ and ‘Maternal beliefs in their child’s training toward

independence' are located on the same level in the centre of the figure. It was also found that these beliefs were influenced by different factors, therefore the theme 'Factors that influence belief development' is illustrated immediately surrounding the two themes in the centre. A major finding was that religious and cultural beliefs inform the maternal beliefs and their influencing factors, and this explains the location of the theme 'Religious and cultural beliefs' in the outer level that surrounds the three themes.

4.3 Maternal religious and cultural beliefs and their relationship with other maternal beliefs

The mothers' religious and cultural beliefs were clearly evident from their interviews. These beliefs were dominant when the mothers were expressing their thoughts about their children's status, their training process and their life journey. While talking about their children, the majority of the mothers expressed their religious beliefs in different ways. On many occasions they showed gratitude to God, ascribed their child's developmental achievements to his power, and their hope of future improvement to his will. For example, when M19, whose son is 10 years old and has moderate cerebral palsy, was asked about his future, she said:

The Researcher: *'One more thing, I would like to know how do you see, let's say, [child's name] future based on his current performance?'*

Mother: *'See, I can't tell you for sure. There is faith in God, Lord of all creations. See, even now, inside myself, I say that regarding his walking, there is nothing that God can't do'.*

Although the mother was asked about her expectations regarding her child's future based on his current performance, she began to answer by clarifying her faith in God and linked potential improvements in her son's walking skills to God's power. This mother's religious beliefs appear to shape her beliefs with respect to her child's likelihood of developing independence.

The majority of the mothers, while talking about their children's abilities, the training process or progression towards independence, used expressions that reflected their gratitude to God's will or power. For example, in most cases when the mothers talked about their child's improvement they said '*Thank God*', emphasising their belief that the child's improvement resulted from God's will. Similarly, when they talked about the training processes they used with their children, and any improvement in the children's abilities, they followed it by saying '*If God wills it*' to stress that they believed that their child's improvement was linked to God's will. For example, when talking about training her child in the future, M6 said:

'*Because my kid is still young. If God wills it, I will teach him in the near future. I would really like to accustom him to using the bathroom, but he keeps urinating*'.

The mother was talking about the child's training here, and inserted the expression '*If God wills it*' before talking about her plans. The spontaneous articulation of this expression reflects the depth of the mother's belief in God, indicating that she may believe that the success of her child's training plan is based on the strength of her own religious beliefs.

Interestingly, when expressing fears for their children and a need to physically protect them, the mothers also referenced God. For example, M7's son is eight years old and has mild cerebral palsy, which causes him to walk with poor balance. She commented that she likes to watch him while he walks to school, to prevent him from falling:

'Thank God, I mean … when he is with me in the car and I go out with him to walk to the school gate he becomes angry because he knows how to go by himself'.

The fact that M7 started by thanking God may suggest that she wants to show both her appreciation to God for her child's achievements, and her trust in God before she talks about her fears, and protecting her son. Potentially this mother is afraid that talking about these issues shows a low level of gratitude to, or trust in, God, and therefore she prefers to start her explanation by thanking God. The same may well apply to the other mothers.

Some cultural beliefs were also identified in the mother's statements regarding their children in relation to their child's potential and training to be independent. For example, *gender segregation* was a motive for some mothers to train their children to be independent. M1's child is nine years old, and has mild cerebral palsy. He had mastered most self-care skills:

> *'I am trying to toilet train him so he can go everywhere freely when I am tired and he goes with his father with the men in some special occasions; that's it. I stop taking him with the ladies. I want him to grow up'.*

The mother here linked the child growing up and mastering toileting with the ability to be separated from her and go to the men's area with his father. Gender segregation while the child is small and in the process of toilet training can be a motive for a male child to be able to go with his father, and a motive to the mother to lessen the burden on her. On the other hand, if the child is not showing progress in developing toilet training and other functional skills, gender segregation can be a source of stress, as after a certain age the presence of a male within female society is not acceptable.

Religious and cultural beliefs can be recognised as coupling many other maternal beliefs, and are suggested to inform these beliefs regarding their children's status.

The ‘religious and cultural beliefs’ theme will be discussed in the following section within three subthemes: ‘relying on God’, ‘religious beliefs’ and ‘cultural beliefs’.

The results chapters will be approached using the approach depicted in Figure 4.1 with the overarching theme, ‘religious and cultural beliefs’ (Chapter 5) followed by ‘factors that influence the development of these beliefs’ (Chapter 8), which impacts on the two central themes ‘Maternal beliefs in child’s potential for independence’ and ‘Maternal beliefs in child's training toward independence’ (Chapters 6 and 7).

5 Chapter 5. Findings: Maternal religious and cultural beliefs

This chapter aims to examine the overarching theme, 'Religious and cultural beliefs'. It will demonstrate how the theme of religious and cultural beliefs was prevalent throughout the data, by illustrating how the subthemes 'reliance on God', 'Islamic beliefs', and 'cultural beliefs,' were captured in the data, and when possible how these factors may have influenced convictions about the child's potential and training.

The diagram in Figure 5.1 was explained in Chapter 4; here the interpretive theme, 'Religious and cultural beliefs' is highlighted clarifying its relationship to the other themes.

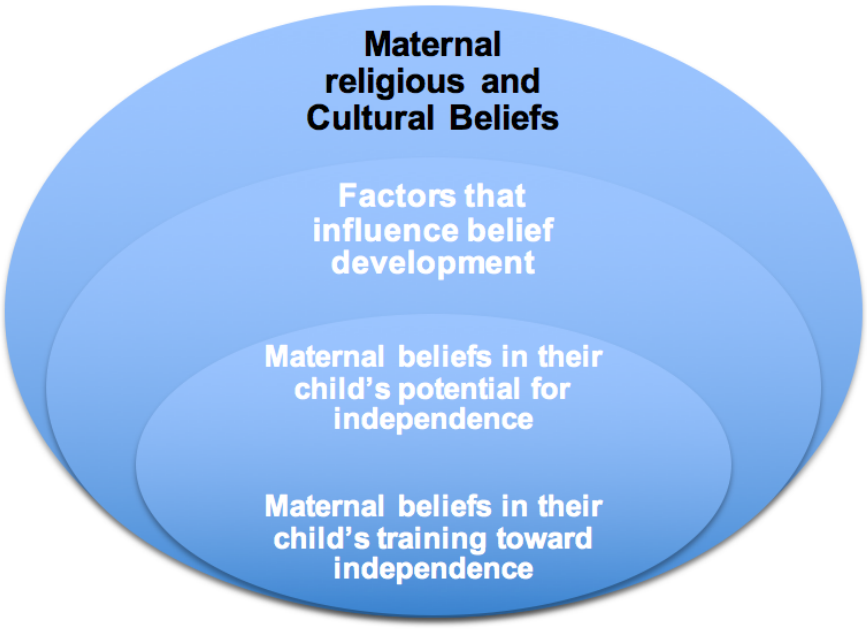


Figure 5.1. Maternal beliefs, highlighting religious and cultural beliefs.

Whilst the importance of religion in shaping people's behaviour in Saudi Arabia has been described in Section [1.4.4.1], data analysis suggested that a closer examination of the mothers' religious beliefs and how they overlap with their beliefs about their children's potential and training – and therefore independence – was required. This theme will capture the mothers' religious and cultural beliefs, and explore how they link to their children's situations. Moreover, it will interpret the ways in which these religious and cultural beliefs can inform and influence the mothers' beliefs about their children's independence. These beliefs will be looked at through three subthemes, which are illustrated in the following figure, 5.2.

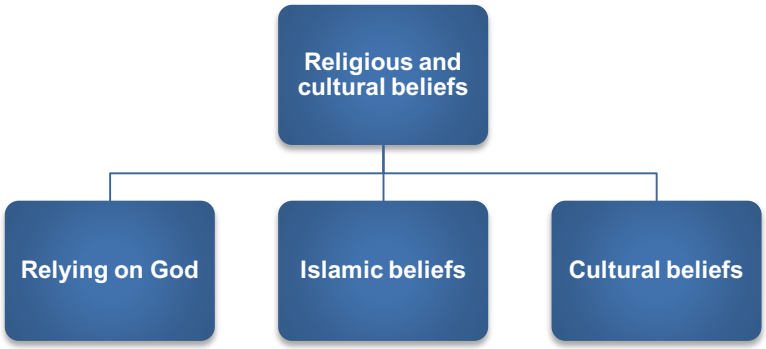


Figure 5.2. Maternal religious and cultural beliefs.

5.1 Rely on God

The power of God

This theme reveals the mothers' belief that their children's current or future capabilities were less the result of training protocols, and more to be attributed to God's will. It was found that the majority of mothers referenced God in relation to their children's situation. For instance, when asked about her child's future, M9, whose son is seven years old, has mild cerebral palsy, and has mastered most of his functional skills, said:

> '*If it is God's will, the hope in God is big. I mean thank God. God, who makes people walk, will help me. If I think he was not walking, then he walked; he wasn't talking, then he talked. Every time something new. Thank God I will not say for sure he will not be better; he will be if God wills it*.'

M9 highlighted her faith in God's will and linked it to what she wanted to say regarding her child's future. She referred her hope and her son's improvements to God, and expressed her gratitude to God about her child's current status while also stressing her trust in God. When the mother talked about her child's improvement and added her appreciation to God, she hoped that improvements would occur as a reward for her faith. The mother talked about the child's improvement in functional skills, linked his previous achievements to God's will, and used the same belief to justify her hope of future improvement. The

mother had previously talked about how she was concentrating on her child's training:

> *'I want him to take care of himself … I have to train him until he goes to the toilet alone, eats and drinks alone … I wish that the day would come when he becomes independent … for example now when he said I need the toilet I go with him and then I stopped halfway and asked him to continue'*

Although her focus was on her child's training, when she talked later she emphasised her reliance on God's will, providing some information about the weight the mother gave to this in her child's training.

Some of the mothers mentioned that their reliance on God is because of their belief that everything that is happening now and will happen in the future is what God wills, so even if they work at training their children, any improvements are due to God's will. M3 mentioned this when she was talking about her child's future. Her daughter is nine years old, has moderate cerebral palsy and has not mastered any functional skills:

> Researcher: *'You don't feel this contradicts with believing and relying on God and so forth?'*
>
> Mother: *'No, if God wills it, I believe in God, I swear to God, and I say if God wills it, she will improve. I am not talking like someone who said "she won't speak after ten years!" "She is ten years old and won't speak" No! Thank God, God is capable of making everything happen. If God wills it, she will*

improve, I don't know, God changes things from one state to another. Believing in the Acts of Allah doesn't mean I shouldn't try to improve her condition, no! I am in charge, I am responsible for her'.

She continued:

Researcher: *'What makes you feel she will walk?'*

Mother: *'If God wills it, my hope in God (Lord of all creation) is big, if God wills it, I am being optimistic, if God wills it. The therapy that I do for her, if God wills it, if God wills it, it will help her. If God wills it, she will get better. As a start, she began, if God wills it, she started a little bit depending on herself, and lifting herself up, thank God, I felt that the past two months, the one and a half months that he [the therapist] has been working with her, the girl started to improve a little bit, somehow, if God wills it. I, the most important thing to me is walking (praying to God) regarding walking, is you say she can walk, she will go to the bathroom, walking solves all the problems*'.

In both extracts, the mother appears to be relying on God by frequently linking her child's improvement to God's will. Talking about her daughter's inability to talk, she states that this might be difficult to develop, but it can be achieved with the power of God, who could dramatically change her child's situation. However, she follows on by mentioning that this would not stop her training her child to improve.

The mother's expression regarding the power of God was an indication of strong faith and being a good Muslim, which would be rewarded by God. It can be understood that even though the mother appreciated training her child to develop her skills, she highly valued the power of God in improving her daughter's abilities regardless of her current abilities. She linked her hope with God and articulated her belief that '*God is Lord of creation*', to justify her dependence on God's power more than the child's progression. This demonstrates that the mother's belief of the reliance on God's power is a clear form of support, which informs her beliefs about her daughter's potential to develop independence during the training process.

Fatalism

Believing in 'acts of God' was frequently expressed by the mothers, as was the belief that everything that happens to people is what 'God decreed' for them, and that God always knows what is best. Most of the mothers mentioned how they depended on God's power and believed this would help them and their children improve, while training their children to improve their functional skills. M10's child is six years old and has mild cerebral palsy. M10 believes that God's power has provided her with strength she did not expect, and anticipates receiving more:

> Mother: *'We were sitting in the living room and I was wondering what I am going to do while he is not sitting or crawling and walking until now, and suddenly he crawled – I*

know you will say I am exaggerating but God is my witness I swear to God. I didn't train him…'

Researcher: *'What did this situation give you?'*

Mother: *'First of all I was thinking that this is a gift from God, and it was as if God was telling me just be patient and I will provide for you and I will compensate it for you; I had a lot of thoughts but I reached the stage where I delegate all my issues to God'.*

Again, M10 attributed her child's sudden development immediately to God. She articulated a deep belief in God's power, considering the progress to be '*a gift from God*'; she believed that she was rewarded for being patient. But her belief in God's power and his ability to deal with all the issues, such as her child's development, caused her to worry. This was revealed in her statement, '*I reached the stage where I delegate all my issues to God'*. After she related her child's development story and showed her trust in God's care, she emphasized her dependence on God in taking care of her issues. M10 asserted, '*I don't care what the doctor says, I have faith and I believe that a day will come; a miracle will come from God'*. The sudden development of her child enhanced her belief in the possibility of a miracle from God. Despite this, however, in the whole interview, M10 appears to be focused on her child's training, and does not seem to rely only on miracles for her child to improve. It appears, therefore, that she

derives strength and support from her faith, which motivates her to be patient and not to become frustrated. This way of thinking might also influence the other mothers' beliefs regarding their children's potential to be independent.

M15's daughter is seven years old. She has moderate cerebral palsy, and had not mastered any functional skills; M15 commented:

> '*Gradually she will get better. Never say there is no hope. The person must have faith in God that anyone who is sick should wait for God's mercy. God's glory has the biggest power and can do anything, sometimes with the blink of an eye. You may see God's glory unexpectedly and He may provide a solution immediately*'.

Again, M15 emphasised her belief in gradual improvement because she was not experiencing '*despair of God's mercy*'; she linked her belief in her child's improvements with her faith in God and his mercy. She mentioned her belief in immediate and sudden solutions from God because he has the power; as if being patient regarding gradual improvement, and having hope and faith in God's mercy would be rewarded with an immediate and unexpected solution. This is reflected in the mother's belief that the child's potential to improve and develop independence could be gradual or sudden. In both M11 and M15's interviews, it was found that they counted on God for their hope, and this helped them to be optimistic, and therefore able to accept slow progress while keeping up the training.

M3 is one of the mothers who used the word ‘frustrated’ many times during the interviews; she appeared to be frustrated by a lack of significant improvement in her child. Her daughter has moderate cerebral palsy, had not mastered any functional skills, and was progressing slowly in developing them:

> *‘I have hope in God Lord of all creation that the girl will improve, if God wills, and Muslims have a great solution which is praying, thank God; as for what the doctors say, it doesn’t get you anywhere. Sometimes, they frustrate you, but you don’t get frustrated; why do we frustrate ourselves, thank God, if you take everything they say literally we would die, but thank God we have hope and optimism, thank God, and my hope is in the Lord of all creation, and thank God, the girl, if God wills it, is going to get better. Human beings always – see I am frustrated – but (there is no power or strength save in Allah), and thank God, oh God, on the contrary. Every time I wake up in the morning, I pray God that she gets better, I see her face in the morning, healthy, thank God that He answers, and she will, if God wills it, improve, and walk. The reports and many things startled me, but thank God I leave them all aside, and I believe in the Lord of all creation and do what I am supposed to do. If I care too much about the reports, my girl would have been dead by now, and finished! But, thank God, yeah, thank God. My faith in God is strong, thank God, oh God’.*

M3 expressed her frustration on many occasions during the interview – in this extract how the doctor frustrated her – but at the same time she emphasised that in spite of what the doctors said she believed in the power of God to resolve things. She clearly drew some strength from such expressions as '*there is no power or strength, save in Allah*'. She linked her responsibilities towards her child with her deep belief in God: '*I believe in the Lord of all creation and do what I am supposed to do'*, and her response to the doctor's negative evaluation was also based on her strong faith. It appears that M3's negative thoughts and feelings conflicted with her faith in God and how she perceived she should act, as a good Muslim. This showed how she depended on her faith as a support during her training journey with her child, especially when facing disappointment because of the doctors' evaluation or her child's slow progress.

Strength of faith

Some mothers also mentioned that having a child with a disability strengthened their faith and their relationship with God. M10's child has mild cerebral palsy and had mastered most functional skills. M10 used to focus on the training; she said about her religious beliefs:

> '*This year something beautiful happened. I became closer to God. You know when people become tired inside they resort to God. This is why I look light-hearted and look carefree, I stopped concerning myself with my surroundings and started taking my issue to God'*.

In this extract the mother talks about giving attention to the spiritual side of her life to reduce her mental stress. She explains that her stronger relationship with God helped her to be able to 'let go' of her worries and rely on God to solve them, which provided support for her in training her child to be independent.

God's justice

Some of the mothers comforted themselves through their belief in God's justice, feeling that God made their children disabled and would compensate them for it in another way. In her interview M1 appeared to focus on her child's training; her son is nine years old, has mild cerebral palsy, and had mastered some functional skills:

> Mother: *'I am not sure if he can do it or not but I encourage him, the human abilities do not stop; the human develops in every stage and, God glory, those disabled children I think they have gifts God takes away on one side and compensates on the other'.*
>
> Researcher: *'How? Tell me more about this point'.*
>
> Mother: *'I mean God said if anything is taken from a human it will be compensated with a good thing; he will compensate for the brain delay with creativity in other things. I try to develop him to see what he can do to benefit his future'*.

This extract displays the positivity that the mother drew from her faith in God's justice and generosity. She wanted to convey the idea that even though her child was disabled and might only develop some skills to a low level, because of God's justice there might be hidden skills that the child could master to '*compensate for the brain delay*'. This belief in God's justice might have supported this mother, and the other mothers, during the training process. Furthermore, the hope that God would be fair with their children would be reflected in the children's development.

Mother's surrender

Some mothers used the belief in 'God's will' in another way, thinking that the current status of their children was what God wanted. This might have made them passive in the training of their children. For example, M4's child is nine years old. She has mild cerebral palsy and had mastered most functional skills. However, she still had poor balance when walking and needed to improve her walking abilities. M4 appeared to be unconcerned about improving he daughter's walking:

> Researcher: *'Do you still think of improving her status to have more balance?'*
>
> Mother: *'No, not any more'.*
>
> Researcher: *'Talk to me about this area, about how you see her current status?'*
>
> Mother: *'I don't think balance is important that's it; that's what God decided for her and I have to accept this from*

God, if it happens ok, if not it is not very important as long she is convinced and accepts'.

M4 did not mention religious beliefs many times during the interview, or link them to her statements. However, here she showed acceptance of the child's current level of achievement as '*what God decided for her*', and was accordingly not working to develop her daughter's balance. The mother used this religious viewpoint to justify her satisfaction with her child's quality of walking. Saying this during a discussion of her child's potential improvements clarifies that she might want this religious belief to guide her regarding her child's satisfaction with her level of independence. Moreover, this belief can be reflected in the mother's motivation and beliefs during her daughter's training.

M11 provides another example of reliance on God's will, in this case in the hope of improving the mother's mental health. M11 put a lot of effort in to training her son, who is 13 years old, has mild cerebral palsy, and had mastered most functional skills. However, he still had poor balance when walking:

Researcher: *'How do you link your trust in God and your training? Do you have limitations because of this trust or does it motivate you?'*

Mother: *'I don't see it this way, I see it for example as the ceiling of my expectation might be very high, but I might say 'I believe in God' this is what he can do! But I will keep trying to make him reach higher from his current situation to avoid making my*

expectation ceiling higher, not because I do not believe that this is an 'act of God' this what God decreed, this is why I always remind myself that this is what God decreed to avoid being depressed and not put more pressure on him; he doesn't have to run or walk normally, at least to avoid danger for example, what he can do – not say this is what God decreed and that's it; not try'.

Here, the mother stated that her belief that God had decreed her child's situation helped her to avoid being disappointed when he did not improve as she had expected. She controlled her disappointment by limiting her expectations using a common expression for Muslims when things get out of control: 'I believe in God'. While this summarizes her deep faith in God's will, at the same time it does not interfere with her working to improve her child's independence. The mother conveyed her understanding of how her belief in God works, and not to take it as an excuse to give up her son's training. This clarifies that where M4 used this belief to accept her child's level of improvement, referring to it as God's desire, M11 separated this belief from her own actions and kept on training her child. It is also worth noting that M4's child is nine years old, and can walk with poor balance, while M11's child still uses a wheelchair to move around. This indicates that when the child reaches their development ceiling, as the mothers see it, they link the child's status to 'what God wants', meaning that God wants the child to reach this level of development. This linkage mostly provides some relief to the mothers, although it will work differently between mothers

depending on the developmental ceiling they put on their children's independence.

God's favour

The mothers linked their children's improvement to their hard work or to being patient (this will be illustrated in Chapter 8, Sections [8.2.3.4] and [8.2.3.4]), but they also paired it with God's favour. M6's child is eight years old, has mild cerebral palsy and had mastered most functional skills. She said, '*We worked hard with him and he became better because of God's favour*'. Although she first acknowledged her own hard work, she attributed the improvements to God's favour. Another time she said, '*his case needs patience and faith in God*'. Here the mother appears to recognize that her child's case needs patience as well as hard work, and this might be an indication of long-term results. She also mentioned having 'faith in God', which she most probably linked with her own patience directly rather than her child's development. Having faith in God will help the mother to be patient and accept the long-term results, which in turn will have an effect on her practices during the process of the child towards independence. The link between the mother's religious beliefs and her beliefs in training her child is manifested when she finds that one of the factors that supports her in the training is 'being patient', assisted by her faith in God.

Invoking faith in God, God's will or power, which together reflect reliance on God, occurs frequently in the interviews, and this largely

reflects the wider Saudi context. In this section, mothers' beliefs, especially regarding 'God', God's will, power and justice, and how mothers derive strength from these beliefs was demonstrated by the mothers' statements. This strong belief may have motivated the mothers to train their children because they believed that they were supported by God's power, to be optimistic because they believed that God is just, and their children's improvement was controlled by God's will.

5.2 Islamic beliefs

Some of the beliefs the mothers expressed in the previous section were inspired by their understanding of Islam. The influence of religious beliefs was obvious in the mothers' statements and understanding; Islamic teachings also have a role in the way the mothers think about life around them. This theme, 'Islamic beliefs', will examine beliefs that have developed from Islamic teachings in relation to the mothers and their children in the light of the mothers' interviews. Each of this theme's interpretive codes represents a belief that is not directly related to reliance on 'God' but is derived originally from Islamic teachings, or at least the mothers' understanding of these teachings.

Fear to refuse God's gift

Some of the mothers frequently repeated their 'fear to refuse God's gift'. It was found that when they felt pessimistic or upset because of

their child's status and thought of it as refusing God's gift, they became worried about being ungrateful to God. M8's son is nine years old, and has moderate cerebral palsy. His mother believes he got cerebral palsy from a virus he had while he was an infant in the hospital, and used to blame herself for this:

> Mother: *'Everyone has weak points that happen to come, sometimes at night I become weak specially when I see him sleeping, I feel bad that he is sick, everybody thinks I am strong but I have weak times when I cry then I ask God to forgive me'.*
>
> Researcher: *'Talk to me about this point more please*.
>
> Mother: *'I used to cry and say I shouldn't admit him to the hospital, I wish that this fever had not come and affected him, I wished I didn't trust the nurses and give them my son and let them make analysis every minute, the virus comes from these nurses but I keep saying thank God for everything'.*
>
> Researcher: *'You just told me that you ask God to forgive you for these thoughts you have, please tell me more about this'.*
>
> Mother: *'I keep saying I wish I took care of him more; if I did he wouldn't be sick and he would be more quiet, but immediately I ask God to forgive me; I know that this is destiny that God decided, that nobody can control, but*

people have weak times, I don't lie to you, but I get back and thank God again'.

When she talked about being upset, and crying, this mother immediately said, '*I asked God to forgive me*'. This reflects her belief that being upset is something that might not be acceptable to God, and when she mentioned her thoughts about being upset, she followed it by thanking God. This reflects a belief that being upset might show ungratefulness toward God and cause the mother to feel guilty. In the interview, the mother looked as if she wanted to vent, tell her story, and express her natural sadness, but at the same time she was careful not to make a mistake towards God. She shared her thoughts about contrition and blaming herself, and explained that she had '*asked God for forgiveness*', adding, '*I know that this is destiny that God decided, that nobody can control, but people have weak times, I don't lie to you, but I get back and thank God again'.* The mother started to express her deep belief that God had decided her life, and then justified her sadness as having 'weak times'; however she mentioned that she deals with her sadness by immediately showing acknowledgment to God. This relates to the mother's beliefs during the training process, when they showed their gratitude to God by saying 'thank God' as a way of displaying their acceptance of God's gift when they talked about their children's status or improvement.

M6's child is seven years old and had mastered most functional skills. M6 shared her impression of when she first learned about her child's condition:

‘When the doctor told me about [child’s name]’s condition, I was surprised, shocked and cried, but thank God, when I came to the hospital and saw the other conditions, I felt much luckier. I never thought about children with special needs before. I got married when I was really young, so I didn't know what to do. I thank God that [child’s name]’s condition is much better than many kids I see; he recognizes his mother, father, siblings, and my family, while other kids can't even recognize their parents. There are kids who have medical devices attached to their bodies, and some can't move, or can't understand. When I see all these complex conditions, I thank God for the things that [child’s name] can still do. What can I do? This is an act of Allah’.

In this extract, the mother is very careful when talking about her child’s case. When she describes her feelings on first learning about her child’s condition, she immediately followed up by saying ‘*but thank God*’. The mother emphasised her acceptance of God’s plans after expressing her upset. She also repeated her gratitude to God when she talked about her child’s abilities, and ended her talk by stating the belief that this was not her choice, but an ‘Act of God’, a conclusive belief to accept God’s gift of having a child with disabilities.

Responsibility in front of God

Some of the mothers felt that taking care of their children was a responsibility they had to God. For example, M2, whose child is seven years old and has moderate cerebral palsy, said:

> Mother: *'I don't want to leave anything on my conscience'.*
>
> Researcher: *'How?'*
>
> Mother: *'I want to clear my conscience in front of God, tomorrow God will judge me over the things I didn't do for him [her son]; for your information I am the one who brought [child's name] here. I took him to Riyadh for treatment, his father did nothing; tomorrow God will judge me if I hear about something and did not do it"*

The mother here mentioned that she was training her child in order to '*clear [her] conscience in front of God*'. It seems that the mother's main motivation in training and treating her child is the responsibility she has before God, and as part of being a good Muslim she acknowledges this responsibility, unlike the father who did nothing. She emphasised her belief that she will be judged by God. This belief of being watched and judged by God, and in being responsible in front of God influenced the mothers' beliefs during their children's training.

M3 also considered her responsibility before God, as shown in an earlier extract: '*Believing in the Acts of Allah doesn't mean if I accept what God gives is not to try with the girl, No I try, I am responsible, God will ask me'.* At the beginning of that conversation, she mentioned that

one speech therapist had told her that her daughter's chances of learning to speak were slim, and she followed this by expressing her reliance on God's power. She went on to clarify that her faith and acceptance of what God had decided for her child did not interfere with her own efforts to help improve her daughter's condition. She linked this to her responsibility towards her child, which she emphasised by saying '*God will ask me*'; in other words, she believes in her responsibility to the child before God. She appears to be influenced by a religious belief, 'responsibility before God' by saying '*God will ask me*', and this belief might have motivated the mother during the child's training process.

Path to heaven

Some of the mothers viewed their situation positively, thinking that taking care of their children might be their 'path to heaven'; this code represents a belief that has a religious impact. M2 said:

> '*I tell them my boy will open the doors of heaven for me. My prayers, fasting, and worship won't get me to heaven, but this will. I feel like he is a blessing for me*'.

'Open the doors of heaven' is a clear articulation of a religious belief related to her child's case. M2 compared all her acts of basic worship with her having a disabled child, and stated that the sacrifices she made for her disabled child would be rewarded by her going to heaven. Her words, '*I tell them*', seems to reveal her pride in this stature in front

of her family and community. M2 appeared to be using the power of religious beliefs in society to elevate her status as the mother of a disabled child, as well as using the uniqueness of her situation to comfort herself. This, in turn, would affect the mother's self-esteem and support her during her journey through her child's care and training to be independent.

In another example M3 said:

> '*This is an Act of Allah and I am content with it. I was upset in the beginning, but I thank God all the time because maybe as my mother said, she is my door to heaven. If I raise her well and bring her up, I will be rewarded. She is a test, and if I am patient, I will be rewarded*'.

In these lines, the mother expresses her gratitude towards God and acknowledges the comfort her mother gave her by referring to the child as her '*door to heaven*'. She believed that if she raised her child well and worked at improving her abilities she would be rewarded with heaven. This was a motive for the mother to work hard with her daughter because she believed that on one hand it would help her child, and on the other it would be a reason to enter heaven. This motive might well influence the mother's training of the child.

Negative devil whispers

Some of the mothers referred to their negative thoughts as 'devil whispers': '*negative thoughts are from the devil*. This is common in Islamic beliefs, as negative thoughts are thought to lead to despair of

God's mercy, and to unwanted thinking. M5's son is eight years old, and has moderate cerebral palsy. Concerning his training, she said:

> '*I used to be very optimistic in my life, not only with [child's name]. I am optimistic that better things will come. I used not to have any pessimistic moments. Sometimes the devil comes to me and says that my child will be a difficult case in society. These are the devil's thoughts; may God forgive me. I don't want to think about the future because the devil will visit my thoughts*'.

The mother believed that she had to stop thinking negatively to protect her faith, and asked for God's forgiveness for having negative thoughts, which she feels are not normal and are the voice of the devil. In another example, M10 said:

> '*If I will talk emotionally for sure I don't want a sick child, I won't lie to you, the devil came to me and told me what luck, imagine your child is normal and goes to school, and I don't lie to you, I think I will need normal child in the future to serve me when I get older and their father gets older*'.

Here when M10 wanted to express some of her negative thoughts, that reflected a sort of objection regarding her status, she referred to them as the devil's words.

One interpretation is that M5 refers to the devil to justify her negative thoughts and to gain God's forgiveness, because after she mentioned her thoughts she followed them by saying 'God forgive me'; but M10 also seemingly wanted to express some of her thoughts about wishing to have normal children, without appearing to refuse God's gift. She therefore referred to these thoughts as coming from the devil. The religious belief that 'negative thoughts come from the devil' might help the mothers to avoid such thoughts while training their children, thereby encouraging them to be positive and more optimistic.

Getting an eye

Another belief that also has a religious impact is 'getting an eye', whereby harm is sent through what is socially called the 'eye' or 'envy', which may destroy health, wealth, or any other positive aspect of life. M5 said:

> '*It was a normal pregnancy, then as I told you it relapsed and got stiff then the placenta separated, so they told me it might be an eye, which made me read more prayers when I got pregnant with his sister*'.

The mother felt that she may have been given the 'evil eye' while she was pregnant with her son and justified that possibility by stating that her next pregnancy was normal. The mother attributes the possibility of outside forces influencing her life negatively, including her pregnancy. As a result of this belief, the mother might attribute the child's

regression or slow improvement to this negative external force. This, in turn, might have an impact on her motives while training the child to be independent.

Mothers' Purity

Some of the mothers mentioned 'purity' as an issue to be considered in toilet training. The issue of ritual purity is essential to perform prayers, and this is invalidated by the presence of urine or stool in the place. M12's child is six years old, has mild cerebral palsy and had mastered most functional skills. The mother focused on her son's toilet training until he had mastered it:

> '*When he urinates he stays in his place and he is not annoyed, but the purity issue annoys us all, you know when he urinates you should do 'wudu' again regardless; you have to wash everything immediately*'.

The mother here highlighted the issue of 'purity', stating that she was annoyed because her child's urine ruined her purity and caused her extra work in washing every time; she used the word 'wudu', meaning washing before praying for purity. This issue might influence beliefs regarding motives in toilet training the child. Another example is M18's child who is eight years old, has mild cerebral palsy, and had mastered some functional skills:

'*Honestly I cannot stand lifting him from here to there if he did it, and I told the teacher they should have a shower for the children because how do they clean the child if all his clothes are covered in urine without showering? And you know I have the problem of impurity and become annoyed when I come and he is sitting then when I touch him I find urine, I become very annoyed*'.

The mother expresses being annoyed while toilet training her son because of it breaking her 'purity', which might in turn influence her beliefs and practices during the toilet training process, and therefore her beliefs regarding the development of her child's independence.

M12 talked about the 'purity issue' causing her to focus more on training her child to be independent when using the toilet, while M18 talked about the facilities that should be in school to avoid such accidents. This religious belief of 'impurity' can occupy the mind of any mother training her child in toileting, and even more so for disabled children who take longer to master it. This could have either a negative or a positive influence on the mother's 'child training beliefs'.

Teaching child Islamic teachings

Some of the mothers talked about their beliefs concerning the 'benefit from teaching children Islamic teachings'; for example, M6 explained how she encouraged her child to pray (her child has mild cerebral palsy and had mastered most functional skills):

Mother: *'If we are not going out, I prepare the pyjamas for him to wear once he comes back. I also encourage him to pray with me, he doesn't know how to pray of course. I place the prayer mat and let my kids imitate me while I pray. I read Al-Fatiha ['The Opening'] and I perform the prayer. On Thursday, we usually go to my parents' house, so I prepare their clothes for them. If we are not going out, they wear pyjamas. They pray and rest for a while'.*

Researcher: *'Why did you emphasise these activities more than other activities?'*

Mother: *'Because [child's name] after few years will be obliged to perform his five prayers every day. It will be easy for him to learn how to pray while he is young; to know how to perform the prayer and know that praying is a must for every Muslim. When he watches his parents perform their prayers, he will realise how important it is. I want him to be close to Allah. When he reads the Quran in the school and while praying, he will be aware of the importance of the Quran, Are you following me?*'

The mother was keen for her child to learn his religious duties (to pray and read the Quran) and to make it part of his training program. Praying requires a level of awareness, and in Islamic teaching it is mandatory for adults and mentally capable individuals. By trying to

teach the child to pray, the mother perhaps felt that her child's awareness was at a level that made him obliged, indicating that she might expect this level of awareness in other activities related to his independence. Alternatively, the mother might have been teaching the child prayers because she believed it to be her responsibility, which she would be asked about before God, regardless of the child's level of awareness.

Another example is provided by M19. Her child is 10 years old, has moderate cerebral palsy and had mastered some functional skills:

> *'With regard to the religious things, he loves to go to the mosque, and I let him go. In the beginning, I didn't want him to go, not that I didn't want him to go, but I didn't want him to annoy anyone. His father said: "Let him go, don't bother, as long as he wants to go, let him go." He started going once, twice, three times, which developed a respect for prayer times; when he hears the call to prayer, he turns off the TV. New things are being implanted in his mind when he is in contact with the outer world. These are the things I care about'.*

She added:

> *'When he started to play with his sister he started to do the praying movements and try to stand like that. I told my self God's glory you never know God might well make him stand,*

he even gets up on on his knees and even his sister started to pretend that he is praying by muttering by the things he used to hear from us; I told my self God's glory, you know these things that I'd love to promote him to do'.

In the first extract the mother expresses how she was pleased that her child had started to practice praying, and respected prayer times and religious teachings; she considered this to be an improvement in his awareness. This belief might influence her views regarding the training of her son to develop social abilities and independence. When she talked about her child pretending to pray, she kept saying '*God's glory*' and asked that his attempts to pray might cause God to have mercy and make him able to stand. There is an Islamic belief that anyone who has mentioned God or has acted in a way that expresses the intention to be closer to God and gain God's acceptance will experience a return of welfare and blessings. This belief provides a possible motivation for M9 and M13 to let their children listen to readings from the Quran and the *athan* (prayer call) whenever they have time.

M13's daughter is seven years old, has moderate cerebral palsy and had not mastered any functional skills:

'*I let her listen to the athan and Quran and ask her to repeat it and pray in front of her, so she can understand that this is a prayer. Because I believe that the two closest things to the*

human soul are the athan and the Quran. I firmly believe that these two things help one understand".

Like M6, M13 believed that when a child learns Islamic teachings, like praying, the Quran will help to improve their understanding and awareness; the next chapter will demonstrate how the mothers linked the child's ability to understand with their ability to be trained and learn from the mother during the training process. If the mother believes that listening to the Quran and *athan* can help to improve their child's understanding and awareness, this in turn might indicate that the mother, according to her religious beliefs, depends on religious practices to enhance the child's understanding, and therefore the child's development towards achieving independence.

In the previous theme, the codes represent Islamic beliefs that mostly relate to the mother's practice with her child, and they appear to be linked to the mother's beliefs during the child's training process. This showed how these religious (Islamic) beliefs might inform the mothers' training beliefs, which in turn relate to the child's development towards independence.

5.3 Cultural beliefs

Child privacy

This theme will look at interpretive codes representing beliefs that stem from cultural impacts and are related to Saudi culture in particular. Some of the mothers had 'child privacy concerns', and mentioned that one of the things motivating them to train their children to master toileting skills was the problem of how to maintain their children's privacy when they became older. M2 believed that when her child grows up, his privacy should not be exposed to her, but it could be to his older brother, so she encouraged him to help her:

> *'I told his brother, who is in sixth grade, when I asked him to help me wash [child's name] in the bathroom, to look after [child's name] when he gets older and will need him more than me. I can't hold him and wash him when he gets older, but his brother can. When I told him that, he laughed because he is still a kid, but I talked to him seriously and explained to him that he has to take care of his brother; hold him, bathe him, wash him'.*

In this extract, the mother talks about how she was trying to prepare her older son who is in the sixth grade (the mother revealed this in another part of the interview) to take care of his disabled brother while he is taking a bath, because it might require observation of the child's genitalia, which is not acceptable, even for the mother, within Saudi culture when the child gets older. Help from a male, in this case the

brother, is more acceptable. It is worth noting that the mother did not try to prepare and train her son to master the skill of 'bathing or washing'; her preparation for child separation was to put the brother in charge of training for this self-care skill. M11's son is 13 years old, uses a wheelchair, and had mastered some self-care skills. M11 stated that she wanted her child to master toileting so that he would be able to maintain his privacy. Unlike M2, the cultural belief of having a 'child privacy concern' motivated M11 to train her child to be more independent, while for M2 training the child was not chosen as an option.

M13 mentioned that she taught her daughter to be aware of her privacy and how to protect herself. M13 focussed on training her child and developing her awareness, she said:

> Mother: *'She thinks she can sleep on any bed and eat any food carelessly. I want her to understand that these are personal things and she has the right to demand them. I tell her the same thing about some body parts, e.g. this is [child's name] breast and this is mom's, and I make her understand that it's improper to show that area to her brothers or any other person except me and her.*
>
> Researcher: *'Continue please...'*
>
> Mother: *'I want her to be able to take a good care of herself in the future; if someone touches her, she screams and protects herself'.*

Researcher: *'How?'*

Mother: *'I ask her sister to unzip her dress and say I will see (the child's name) thing. When I see it, I tell her it's a shame to show it to anyone'.*

The mother explained here that she is teaching her child how to be careful, to remain covered and protect herself from abuse. Although being worried about abuse can not be considered a cultural belief in Saudi Arabia, covering the private areas – and there is special emphasis if the child is female – is a cultural belief. In this example, this belief encourages M13 to train the child how to be more aware and how to cover herself, which might be part of the 'dressing' skill, and also how to defend herself, which is included within social skills. This motivated the mother to train the child to be more independent.

M16 reported that when her daughter dressed herself, she sometimes walked out of the room while not fully dressed, which was unacceptable because her father and brothers might have seen her. The mother mentioned that she rebuked her child, asking her to go and dress immediately. This cultural belief motivated the mother to train her child to master the dressing skill so that she would be able to cover herself. In most cases the cultural belief of the mothers' concern for their child's privacy informed their training process and spurred the mothers on to train their children to be more independent.

Gender segregation

One of the Saudi cultural beliefs that some mothers mentioned when they talked about their children's cases was '*gender segregation*'. This motivated some mothers to train their children to be more independent. For example M1, whose son is nine years old, has moderate cerebral palsy and had mastered most functional skills:

> '*I am trying to teach him to go to the toilet to help himself when I get tired, or when he goes with his father to a special event where I can't take him to the ladies. I want him to develop himself*'.

In Saudi Arabia, some societies do not accept even little boys being at ladies' gatherings such as wedding parties, Eid events, or even simple gatherings. Here, the mother stated that separation from the child was a motivation for her to toilet train him; this cultural belief influenced her in her son's training process.

M2 had the same concern:

> '*I even bring him here [to the centre]. If tomorrow he goes to school, I can't go with him or talk to his male teachers face to face, or go into the classroom and see what he is doing. I want him to know how to push his wheelchair and go inside and outside, to know how to go to the bathroom and know how to say that he needs to go, to eat by himself, drink by himself. I want him to be able to do these things all by himself*'.

Although throughout the interviews M2 did not reveal the intention to train her son in self-care skills (as also explained in the previous cultural belief 'child privacy concern'), she said that she had no problem doing these self-care skills for him while he concentrated on training to walk. However, when she talked about her child's future, when he would become separated into the adult male section, she stated that she wanted him to learn self-care activities and how to communicate when he is away from her. The cultural belief of gender segregation became a motivating factor that influenced the mother's belief in the training process towards separation and development of independence.

M5 sees gender segregation as a source of worry, rather than a motivation to train her son, who is eight years old, has moderate cerebral palsy, had not mastered most functional skills, and has slow progression:

> Mother: *'In the short term I am optimistic but I think when he gets older, becomes an adult, about how society will deal with him. I mean a disabled adult is much more difficult than a child [cries]…When he becomes older they will be scared of him they will not think he is sick, men will see him under their eyes… I feel I can do a lot for him when he is young but when he gets older, I can help him in walking, but I can do nothing with his understanding of people staring [at him] in the future; while he is young people will still see him as a*

child but when he is old with a beard, how the situation will be I don't know, and this is worrying me a lot and I am trying to be realistic'.

Researcher: *'I am listening, if you want to continue, and you can take your time'.*

Mother: *'Ahhhh, you know how it will be when an old lady for example passes by him when he becomes older, for sure she will not accept, she will say he is staring at me and so on, for sure westerners don't have all of these worries, only we have them'.*

The mother expressed her worries about the future when her child would become an adult, feeling that he would not be accepted in female company because of gender segregation. Moreover, she mentioned that women might be scared of her child when he becomes a disabled adult. At the same time she believes that if he goes to the male areas he will not be respected because of his disability: '*men will see him under their eyes*' is a direct translation of getting an 'inferior look' from other males. The mother understood this to be a unique feature of Saudi society: *'westerners don't have all of these worries, only we have them*'. This reflects a feeling of unfairness, in that even if her child becomes, to some extent, independent in male society, she will still worry for other reasons.

Image of being a man

Some of the mothers also used the belief of the 'image of being a man' as a motivation for their children to achieve mastery over self-care or mobility skills. For example, M8's son is nine, has mild cerebral palsy and had mastered most functional skills. His mother used the description of a 'man' to motivate him to dress himself:

> '*For example, he was refusing to dress. I tried with him, asked him to watch his brothers and how they dressed alone; then finally I told him: "See, your father dresses by himself. If you want to be a man like your father, you have to dress by yourself". Then he started to like getting dressed and asked me not to come and help him get dressed'*.

Using the father as an example of a 'man' motivated the child to change his behaviour from refusing to act independently to working towards being independent. The mother recognised the impact of this on the child; this cultural belief influenced her training techniques and the way she felt independence could be achieved. In M8's case however, this notion played out differently:

> Mother: *'If I come to talk to him and convince him to accept training he leaves me and goes away; he says 'because you are a lady and I don't like sitting with ladies or accepting orders'.*

Researcher: *'Where do you think he's getting this talk from?'*

Mother: *'Maybe he is mimicking his father.'*

The mother feels that her child does not accept her training because she is a woman. She recognises that her child discriminates between men and women, and wants to be trained to be like a man, which could be motivational. However, his refusal to be trained by her because she is a woman is an impediment to his training. The phrase 'become a man' was repeated frequently by the mothers when they explained how they encourage their male children, and although this might not be related specifically to Saudi culture, it might apply more generally to this male-dominated part of the world. Moreover, it is more a cultural than a religious belief.

Gender-related differences

Some of the mothers mentioned that they perceived a gender-related attitude difference towards disability in Saudi culture. For example, M2's son is seven years old and has mild cerebral palsy. She had concerns over stigma towards disability when her child was born:

> *'I thank Allah that he is a boy because it is hard for a girl with special needs. The girl's view is different from the boy. For example, one of the mothers here has a daughter and the way the daughter looks at her mother makes me feel that she blames her mother. I feel that when she looks at her mother she says to herself "why I am like this?" the girl is only five*

years old. I don't say that the girl's said that; this is the feeling I get from the girl's looks. She is not smiling. She always buries her smile. She feels shy because she is like this. The boy's situation is a little bit better. I don't know why. He is better on all sides, but I don't know how.

For example, it is hard for a girl to deal with the menstrual cycle, how to act and clean herself. Also there is a limited number of people who can hold her. For the boy, everybody can hold him. For the girl, only her father, her mother, or her brother can hold her. When I hold my son a stranger can help me, this is hallal [allowed by religion]. It is the opposite for the girl, it is haram [not allowed by religion], only her male chaperones can hold her. This is what I want to say to you'.

M2 believed that disabled girls are in a worse situation than boys, mentioning the difficulty that disabled girls experience in keeping clean during their menstrual cycle and revealing the differences experienced by male and female children in a certain situation; boys have no problem being carried by a man, even if that person is from outside the family, but a girl can only be held by one of her close relatives (brother, father, uncle). These beliefs might make the mother feel that only limited choices will be available during training when the girl is older, which in turn may influence the mothers' beliefs concerning the training process of the child towards independence as a whole.

M6's son is seven years old and has mild cerebral palsy. She believed that having a disabled boy is better:

> '*He might work and study and go out in society. [child's name], because he is a boy, he goes out with his father and makes friends. Now he goes with his father to the sports club, and he is very happy. Thank God*'.

She believed that because he is a boy, her son can freely go out and experience separation and social activities. He can go out with his father and therefore can learn more, unlike a girl, who in some Saudi societies has fewer opportunities to go out. In addition, the mother believes that as a male, he has more opportunities to study and work. The mother is therefore more optimistic about her child's chances of developing independence in the future, because he is a boy.

On the other hand, M13, whose daughter is seven years old with moderate cerebral palsy, believes that it is better to be a girl because her mother can keep her close and take care of her. When describing 'gender segregation', M5 worried that her child would be isolated from women in society when he becomes older, and this is a sign that she believes being a disabled boy is more difficult because of the segregation.

In this interpretive theme, some of the mothers expressed beliefs that are specifically related to Saudi culture, unlike the 'Islamic beliefs' interpretive theme that applies to all Muslim mothers. Although all of the mothers in this study are Muslim and Saudi, the degree to which they

adhere to these cultural and religious (Islamic) beliefs varies between them. These beliefs were considered to have a potential impact on their views about child training and their children's potential to be independent. The mothers' concerns regarding their children's privacy and preparing for near future gender segregation encouraged them to train their children to be more independent, also using the image of being a man. At the same time some mothers linked the fact of being a boy or a girl to the child's chances to improve, linking it with cultural beliefs related to Saudi society.

5.4 Conclusion

This chapter presents the main findings of the study. It examines how religious and cultural beliefs in depth and appeared to influence the mothers' beliefs regarding 'child potential and training beliefs'. Although the context of the interviews did not focus directly on exploring these religious and cultural beliefs, they were prominent and appear to be strongly related to many aspects of the mothers' beliefs and behaviours regarding their children; the focus during data analysis was toward the mothers' beliefs about their children's training and potential to be independent. The majority of the mothers displayed a reliance on God and showed their gratitude to God when they talked about their children's training process or improvement. This influenced the mother's beliefs concerning the child's potential or their training towards independence. Moreover, some of the mothers linked their Islamic and cultural beliefs with the practices they employed with their children, and

they appeared to be an influence on their beliefs in their children's potential and training. However, it is important to mention that all of the religious (Islamic) beliefs that were within the theme, and most of the cultural beliefs, are held by the majority of the mothers as Saudi Muslims living in the same society, regardless of whether they expressed it or not. The relation of these religious and cultural beliefs to the mothers' beliefs regarding their child's potential and training, and the factors that contribute to the construction of these beliefs will be also highlighted in chapters 6, 7 and 8.

6 Chapter 6. Findings: Maternal beliefs in the child's potential for independence

This chapter will explore the mothers' beliefs regarding their children's potential in relation to their independence. The diagram in Figure 6.1 below shows the interpretive theme, 'beliefs in their child's potential for independence', and its relation to the other themes.

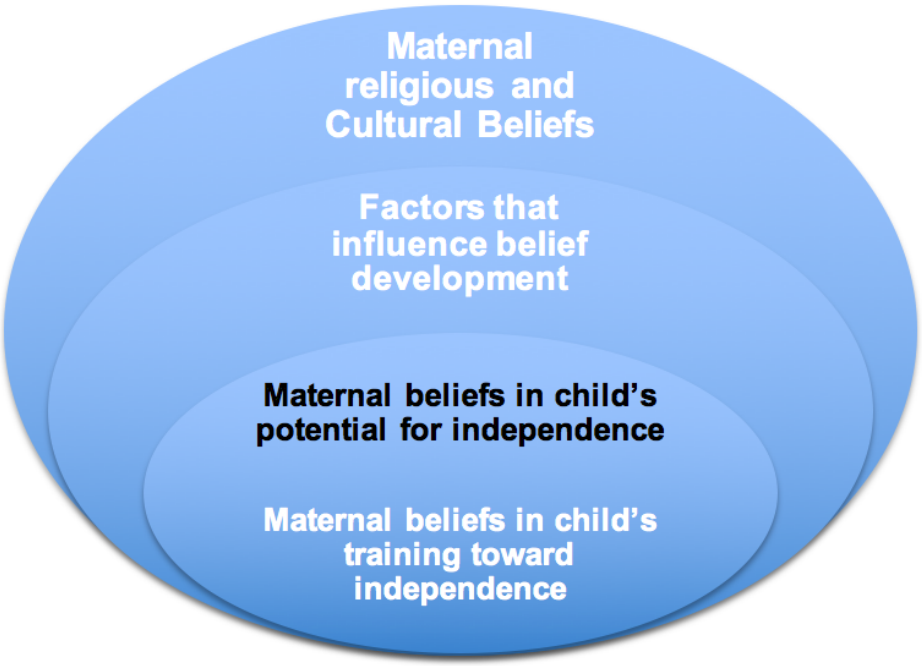


Figure 6.1. Maternal beliefs, highlighting mothers' 'beliefs in their child's potential for independence'.

This will be demonstrated here within two subthemes, first 'mothers' understanding of independence', which will explain the different understandings of child independence between mothers (cognitive,

personal, and physical), a main finding concerned with the mothers' understanding of independence. Each domain included the aspects of a child's development that the mother believed to have the potential to enhance the child's independence. The mothers offered different interpretations and had different priorities in relation to independence ranging from a focus on their children's cognitive abilities and ability to understand to the need for walking, self-care or social skills. The priority that they placed on these domains provided a better understanding of what represented independence for these mothers, and therefore their beliefs regarding independence.

The second theme is 'beliefs in child's functional ability', it will focus on the beliefs regarding the mothers' expectations of their children's functional abilities, and beliefs regarding the mothers' support toward their children's abilities (Figure 6.2).

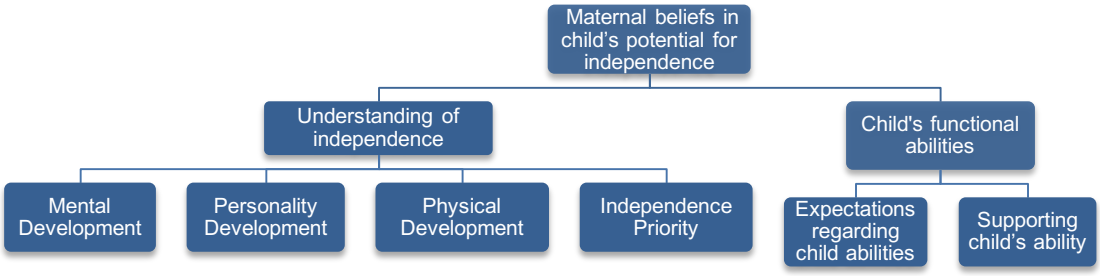


Figure 6.2. Subthemes of the theme 'beliefs in their child's potential for independence'.

6.1 Mothers' understanding of independence

All mothers expressed their understanding of independence through their beliefs in three domains: cognitive development, personality development, and physical development, and in most cases they prioritised their focus during training (Figure 6.2).

6.1.1 Cognitive development

In this study, cognitive development refers to the child's ability to understand the mother's instructions, the ability to understand her demonstration of the task, and the ability to understand his or her own surroundings. The findings showed that when the mothers talked about understanding, they did not aim to achieve a complex cognitive ability that included high-level thinking, such as participating in detailed conversation or memorising complex orders. The mothers mainly referred to their children's understanding of simple guidance and having a general awareness of their surroundings. This manifested with M1, whose son is nine years old with mild cerebral palsy. The following extract clarifies how the mother links the child's understanding with his awareness or surroundings:

> *I tell him that when it's dark, we go to bed, then wake up in the morning and go to school. He understands then and goes back to bed. When he understands what I say, he will depend more on himself. Now, he started to understand more and depend more on himself.*

Some mothers did not mention the value of understanding, possibly because it was not a priority, or they were satisfied with their children's level. Some mothers mentioned that they appreciated their children's level of understanding, especially when they talked about their choice of learning style. Many of the mothers stated that their child had evidenced understanding. These mothers chose a verbal learning style in guiding or training their child in different skills because they believed it was the most powerful; they described a task depending on their child's ability to understand and follow their guidance. This suggests that the children's level of understanding was a factor in the style the mothers used to train them, and also that the majority of them believed in the value of the child's understanding in developing independence. In this section there will be examples of mothers who mentioned the value of understanding, believing that 'understanding ability' played an important role in developing their children's independence, particularly in relation to the development of self-care skills.

The following examples are of mothers who linked their children's ability to understand with the learning of self-care skills. M1's nine-year–old son walked with assistance, and was in the learning stage of self-care skills although he had not yet mastered them all. M1 was asked about linking the improvement of his understanding and developing his independence:

> *'When he understands, he can depend on himself. I want him to discriminate between the right and the wrong behaviours. When he knows that he has to go to the bathroom, when he*

needs to do something, this will help him be more independent. I feel that he doesn't have bladder control because he still doesn't understand; that's why I need to teach him persistently. Sometimes, he plays instead of finishing his meal, and he feels hungry shortly after that. He doesn't understand that if he eats a bigger portion, he will feel full. He needs to understand that by himself in order to be more independent. Similarly, he doesn't understand that he has to go to the bathroom when he needs to, like normal people; he does it in his diaper instead'.

M1 linked her child's ability to master toilet training and eating with his level of understanding. She believed that because her son's level was low, he was unable to understand when he needed to eat or use the toilet. She also believed that he was unable to understand her instructions about how to practice these skills. The mother recognized the need to develop her child's understanding, and prepare him to be independent.

M13 believed that understanding was important in helping to develop other functional skills that related to independence. She prioritised her daughter's understanding, helping her to learn the skills required for self-care. M13's child, a seven-year-old girl with moderate cerebral palsy, had not fully mastered her functional skills. She was trained in mobility skills at the centre, while her mother focused on improving her self-care skills at home. Asked to explain the reason that she valued her child's ability to understand, M13 said:

> '*I feel if the person has no understanding, she becomes careless and has no personality and no life, like a blank piece of paper. When I first brought her home, I said I wanted her to be normal, but now I just wish for her to understand*'.

M13 felt that her child's cognitive development and level of understanding gave her value in life. Previously, she had referred to her daughter as having '*no understanding … no personality*'.

M13 also linked the child's ability to practice skills such as dressing or grooming (i.e., self-care skills) with her ability to understand:

> '*She uses her hands to carry things and comb her hair and dress, and as long as she understands and has good hands she can do it, but if her hands are good but she does not understand, she will not know what these hands are and what to use them for*'.

This response demonstrates her belief in the role that understanding played in her child's ability to learn, practice and combine self-care skills. She believed that while her child might have physical abilities, such as strong hands in terms of the ability to grip and control, without the ability to understand how to practice, her daughter would not benefit from her physical ability.

M8 also linked the ability to learn self-care skills with her child's ability to understand. Her son, a nine-year-old with mild cerebral palsy, was at the stage of developing self-care and mobility skills. In the second

interview with M8, she was asked about her child's progress in learning self-care skills. She described his improvement in the ability to dress himself compared to the previous year, when the first interview was conducted. However, she also linked this improvement to his level of understanding:

> '*He understands now, compared to last year. When he wants to wear his shirt, he knows where to put his head and arms*'.

M8 explained that her son's ability to understand was related to his ability to learn how to dress himself and she realised that he was gradually developing this ability.

In these examples, the mothers explained why they valued their children's ability to understand and stated that they believed it helped their children to learn self-care skills. For example, M10 said that because she knew her child understood, she challenged him by giving him complex instructions:

> '*Before, I used to ask him to bring his fathers' cap or to bring the bread; now I ask him to open the fridge and bring mango juice, for example. The other day his father, who laughed at me when I first started to train him, asked him to bring chocolate from the fridge, but he brought cheese. This time I laughed, but at least he tried*'.

M8 recognised that an order involving multiple steps was more advanced. She believed that her child had developed from understanding a single order to bring the bread, which was usually on the kitchen table, to understanding a more complex instruction to open the fridge and recognise one item from among several others. M8 believed that training her child to understand her instructions would help him to master the functional skills needed for independence.

Some mothers believed that their children would achieve independence when they were able to keep themselves safe, which could be achieved through understanding danger and being aware of their location. M8 said that she was greatly relieved because her son's understanding was better and he could find her if they got separated while they were in the park. She linked his understanding with his recognition of locations, which meant that he could play in parks more freely and independently. M1 succinctly expressed the value she gave to her child's ability to understand: '*If he understands, he will lead his life*'. The phrase 'lead his life' reflects M1's belief, and possibly the beliefs of the other mothers, that the ability to understand could allow their children to control their own lives.

The findings revealed that the majority of the mothers believed that their children's understanding was a prerequisite for teaching them functional skills, and expected them to learn, practice and gain independence, including being safe from danger. However, the findings indicated that such independence was related to self-care rather than independent physical mobility.

On the other hand, some mothers mentioned that their children's high level of understanding, although helpful in developing independence, might result in some of the children making a deliberate decision to depend on other people. M5's eight-year-old son was confined to a wheelchair and had not mastered all self-care skills. M5 talked about some recent progress her child had made, linking it with his level of understanding. She was asked how she would link this progress with his current and future development:

> *'Understanding helped him to depend on himself. With me, when I give him an order, he will do it, so this has helped him and will help him in the future. If God so wills, he will walk. I have started to talk with him, you know, about how to walk, "but first we just need to solve your back problem". I feel he understands, but at the same time, his understanding lets him down sometimes; he loves to depend on people, so he is using his smartness to hold him back, and this is really annoying. Some sick children use their smartness to hold them back. He will think "if I walk, my mom will leave me and let me depend on myself". I feel he understands it in this way; he is smart, and if you sit with him, you will know he is very smart in this way'.*

In her response, M5 expressed several beliefs. Her child could understand her orders; she prioritised walking because it was important that he mastered this skill; her child used his intelligence to obtain more support and to remain dependent, and because he was 'smart', he

avoided practicing independence to maintain his mother's support and attention, which would have negative consequences. However, M5 did not mention any action or feedback in response to her child's behaviour.

M2 believed that her child had a good level of understanding. When she was asked how she had determined his level of understanding level, she said:

> '*He can differentiate friends from strangers, his mother from his father, his siblings, his cousins. He imposes his opinion when he wants something'.*

She also linked his level of understanding to his occasional intransigence. When she was asked about how she handled her child's safety and use of sharp objects she said:

> '*When there are sharp toys, I tell him to stay away from them and not to play with them because they will injure him, or hurt him, and he understands. Sometimes, however, he opposes what I say. He is a little bit mean* [laughing]*, but he knows it. I feel that he is smart; that's what makes him stubborn or manipulative*'.

M2 focused on her child's level of understanding when she complained that he ignored her warnings. However, she interpreted the child's level of understanding by referring to it as his intelligence ('*he is smart*'), which indicates that she did not perceive his intransigence entirely negatively, nor did she appear to be worried about it.

Similarly, M18 stated that because of her child's level of understanding, he was sometimes aggressive and intransigent because he knew he would get what he wanted. This finding showed that some mothers who believed that their children had reasonably high levels of understanding did not find it helpful or positive, but rather that it led to negative behaviours. However, the majority of the mothers felt that their children's ability to understand would allow them to develop independence. Although this ability to understand was not directly linked to independence, the findings showed that the mothers emphasised the *value* of the ability to understand, and thought that it would contribute to the development of their children's functional skills, thereby helping to develop their independence.

6.1.2 Personality development

In the interviews, many mothers talked about features of their children's personalities, such as weakness, shyness, confidence, and strength. Only a few mothers linked these traits with their children's development of independence, and instead explained their beliefs about developing their children's personalities. Describing how they encouraged their children's personality development these mothers either spoke generally about strengthening their children's personalities, or specifically about increasing their confidence and self-esteem. This is different to the way some of the mothers acknowledged their children's smartness or advanced level of awareness of their surroundings; in this case the mothers worked on promoting the children's personalities in

order to develop their social abilities with the ultimate goal of achieving social independence.

M14's seven-year-old daughter with mild cerebral palsy had mastered most of the self-care skills. Her mother mentioned a recent change that had occurred in her personality:

> *'Her personality is such that she quickly becomes nervous and moody and hard to control; I am having some psychological consultations to find out how to deal with this, especially in those times when we lose control when we are outside. She refuses supervision and becomes very nervous if she finds me watching her from a distance. She wants to be alone; in the times when she is moody she wants to eat her dinner alone, for example. It makes me feel that she has her own opinion now … for me, her personality change is something positive and this means she is smart'.*

Although M14 initially described her child's personality changes as negative, she also referred them to as developmental, which can be interpreted as positive. The mother mentioned that the child chose her own meal times, and had started to choose her outfits, aggressively refusing supervision. She considered these developmental personality changes to be positive signs of her daughter's increasing intellectual level, which gave her hope of further improvements in her daughter's independence. These findings exemplified the mothers' attitudes toward the development of their children's personalities, which they believed

might be linked with the ability to develop other aspects of independence.

The research also showed that some mothers linked the development of their child's personality with the child's insistence on achieving higher levels in their mastery of functional skills. For example, in the interviews, M6, talking about her son with mild cerebral palsy, linked the development of his personality with the development of his self-care and functional skills. When she talked about choosing her child's clothes, she said that they sometimes did not agree on what he should wear, but she did not force him because of his independent personality. When she was asked to explain what she meant, she said:

> '*I mean I don't push against his personality; everyone should have an independent personality, don't put pressure on him in everything, there are things that we discuss: "why you do not want this?" then he tells me why and we discuss it; then he started to establish his personality*'.

M6 mentioned that she cared about her child's personality and so did not pressure him into making decisions. M6's explanation did not reveal any link between her child's personality and his disability or performance. However, in the second interview, she described her child's personality as strong, saying that he '*insists on the thing that he wants to do, and said this gives him a chance to interact with people*'. M6 linked the strong personality of the child with his insistence and

desire to interact with people. When she was asked about her reasons for encouraging him, she said:

> *Mother:* 'When I make him feel that he is doing something important, this strengthens his personality'.
> *Researcher:* 'How do you feel his personality will help him gain independence?'
> *Mother:* 'When being independent, he will say "I can do this"; for example, by walking in the walker or climbing the stairs … a strong personality means he will insist on the thing that he likes and impose his opinion on his siblings'.

M6 believed that because of her child's strong personality he insisted on succeeding and believing in himself, and this prompted him to practice and master the skills of independence. This mother also highlighted her child's ability to express his opinion and to assert his rights because of his strong personality. The same belief was expressed by M11, who also linked her child's strong personality with his insistence on asserting his opinion. M11's son, with mild cerebral palsy, walked with assistance, but had mastered most self-care skills. M11 focused on developing his functional skills and providing him with continuous training. When she was asked to evaluate his personality, she said:

> '*If we compare him with normal children I see that his behaviour is close to normal, but if you want to see him as sick*

you will say he is the opposite. But if I want to be realistic, he insists on wearing this outfit not that, or these shoes; not that I name this personality strength, because when I talked to him he listened'.

As mentioned, M11 linked her child's strong personality with him insisting on making his own choices, which she considered normal. In addition, when she was asked whether it had any influence on independence, she said:

'*Let me say that this gives a positive influence and [child's name] started to depend on himself more and the physical and strength "centre" is clear and this is positive – he started to be an understanding child*'.

This finding showed a relationship between M11's description of her child as having a strong personality and his development of independence. She also linked it with the development of what she called a 'physical centre' – referring to what might be interpreted as his physical ability – and to his comprehension ability. This finding indicates that the mothers who focused on developing their child's personality because it was linked with their independence believed that it had a positive effect on their children's progress.

M12 focused on her child's social abilities. When asked how she related the development of his independence to the development of his personality, she responded:

> '*Thank God he understands, but not that much; but he understands, especially in social things. There he is good, when he sees a car he asks whose car it is. That's why I particularly want him to like using the toilet, so that socially, when he goes to people, he can keep himself and his clothes clean, and, as they say, protect his image*'.

She added, *'When he develops in school and they say he is socialised, or I see him treating people in a nice way, I feel optimistic that he will get better*'. The findings showed that M12 focused on her child's social abilities and that she encouraged him to develop them. She linked the development of his understanding and self-care with the development of his social functions. The findings also indicated that she appreciated his level of understanding because she linked it with the development of his personality and social performance. M12 valued her son's abilities and viewed them as a sign of his developing independence, believing that it might be a sign of his future development and improvement. She linked her child's personality development with having good social abilities.

Similarly, M19 also focused on her child's social abilities. She stated that her son's 'shyness' influenced his performance. M19's son, a 10-year-old with mild cerebral palsy, had mastered most functional skills. He was able to walk by himself with the aid of a walker but he preferred to sit in the wheelchair. His mother referred to his personality when she

talked about his training, particularly his dislike of using the walker in public. M19 said, '*He is shy about himself in such areas but I started to promote him*'. This mother showed her understanding of what she believed regarding her child's shyness and linked it with his own thoughts about his situation. She mentioned that she had encouraged him to go to the family's social gatherings and wear traditional garb:

> '*He started to love these places and link it with wearing* Gotrah *and* Ekal *[traditional hat] then slowly started to gain self-confidence and join people*'.

M19 talked about her focus on developing what she believed to be her child's self-confidence by encouraging him to socialise and interact normally with his siblings, saying, '*[I] want them to be normal*'. She believed that asserting himself among his siblings would help to '*remove his shyness barrier'.*

Similarly to M19, some other mothers focused on their children's ability to defend themselves because of their strong personalities. M2 mentioned that her child fought with his siblings. Although her son, with moderate cerebral palsy, had not yet mastered most functional skills, M2 did not link this delay with his personality. She said that she disciplined him in the same way as her other children, and was satisfied that he was strong and able to express himself, which linked to her belief that he could defend himself. The children's ability to defend themselves was one of the concerns that the mothers expressed about social separation from the child, and the children's need to depend on

themselves. M2 believed that by allowing her child to assert himself, she was helping him to protect himself from being assaulted by other children. It was unclear, however, whether M2 and M19 considered their children's aggression in their surroundings to be part of having a strong personality, which would help them to gain independence. Both mothers mentioned their children's physical ability to defend themselves but focused on the development of their personalities.

Most of the mothers talked about features of their children's personalities. However, not all of them described how they worked to develop them. The findings showed that they also believed that their children's assertiveness would enhance their ability to achieve high functional and social skills, which would enable them to engage in society and become independent. The children's assertiveness would also improve their ability to defend themselves, which then would encourage the mother to separate from their children, thus further facilitating their independence. These findings yielded insights into the mothers' beliefs regarding the development of their children's personalities, as well as the ways in which they linked developmental aspects of their plans to help their children achieve high levels of independence.

6.1.3 Physical development

Several mothers highlighted the value of mastering balance and discussed how it had influenced the development of self-care skills. For example, M3 and M13 noted that their children's poor balance delayed toilet training. Both children were in wheelchairs, and they had not

mastered most functional skills. The mothers described trying to train their children to master toilet training; while their children had poor balance they were unable to hold themselves up while seated on the toilet, which made it difficult for the mothers to leave them alone. M13 said that her daughter was able to control her evacuation, but could not balance herself on the toilet:

> '*When I take her to the toilet I have to hold her all the time and wait. Sometimes I told myself I was not patient. I did everything for her, except toilet. If she just can hold herself while sitting on the toilet I will be able to take her to the toilet and let her sit, because now I have to hold her all the time*'.

M13 said that although her child was able to control her evacuation, she had not mastered the balance needed to sit unsupported on the toilet, so M13 had to hold her, which made toilet training difficult. M3 and M13 might have believed that mastering this aspect of physical development was a prerequisite for mastering the self-care skills that were necessary for the development of independence. Other mothers mentioned that because of their children's poor balance, they supervised them to stop them falling, and this would potentially delay the mother-child separation.

Most of the mothers in this study talked about training their children to walk, which might have reflected their belief that mastering this ability signalled their child's independence. However, the mothers varied in

their focus on this skill. The following examples highlight the reason that some mothers focused on developing their children's walking ability.

M15's daughter had few self-care skills. Although she could balance in sitting and in training she had not yet mastered walking. M15 believed that walking was important:

> '*I want her to walk to release some of the burden on me, to stand up, to go with her brothers and sister; the older she gets, the heavier she becomes, and the harder for me to carry'*.

M15 linked developing her child's ability to walk with lifting some of the physical care burden from her, which she noted was becoming increasingly difficult for her as her daughter got older and gained weight (reduction of burden will be explored in Chapter 7). Other mothers also emphasised the physical burden of caring for their children. This finding helped to clarify one of their motives for improving their children's mobility and training them to master walking skills. As well as this, the mothers believed that walking would enable their children to share activities with their siblings.

Similar to M15, M13 recognised that walking was a pivotal achievement that might encourage her child's social activities. She assumed that if her daughter were able to walk, she would be happy and enjoy being like a normal child:

> '*I wish that she could tell me that she wants to walk like a normal child because when she sees the children playing around her, she becomes happy, and when they go away she starts to stare after them and looks as though she is thinking "What is this world that moves around me, and I am always waiting for them to come to me?". Sometimes I take her out of the wheel chair and leave her on the floor to encourage her to crawl and follow them'*.

M13 wanted her child to walk because she assumed that she wanted to interact with the other children. She referred to a walking child as a 'normal child', and believed that her daughter's poor speech prevented her from expressing this desire. This mother focused on the children's interactions and did not mention that mastering walking would develop her child's independence in mobility.

This revealed that M13 believed that her child was excited about mastering the ability to walk because it would enable her to join in activities with other children.

The findings also suggest that some mothers believed that their child's ability to walk could encourage them to learn self-care skills such as sitting unsupported on the toilet. For example, M5 talked about the value she believed there was in mastering walking although her son was still crawling or using a wheelchair. With regard to training him, she said:

> '*I am optimistic that he will walk; of course this will develop his brain, I mean he will understand when he walks that he should go to the toilet and can go to the place he wants. At every step the human takes, his brain is instructing him; even in adults their brains know where to take them. I want this stage for him; that's why I insist that he walks. I want him to develop and then to depend on himself*'.

M5 believed that mastering walking played a role in developing cognitive ability and self-care skills and that it would help her son to gain independence in general. Walking, therefore, was highly valued in this mother's beliefs because it contributed to the development of other skills.

Some mothers recognised the value of walking for their child's participation in society. For example, M13 and M19 both articulated their recognition of the general impression of having poor walking ability. In describing and defending her daughter, M13 said:

> '*She is a normal kid, just like any other kid, but she can't walk. Treat her in accordance with her mentality, and she will understand; she can discriminate*'.

M13 insisted that she perceived her child to be normal, linking this to her levels of understanding and cognition while talking about her

inability to walk. She recognised that evaluations of her daughter's abilities might be based solely on her poor physical abilities, but believed that her child's physical disability had little to do with her classification as normal or otherwise.

M19 shared M13's belief regarding societal assumptions about the inability to walk:

> '*There are some mentalities that think since they don't walk, they are really stupid, buried and dead! They would expect everything negative from them! This is how they think*'.

M19 believed that some people in society assumed that the inability to walk was linked with the social and cognitive abilities of the individual and was associated with diminished cognitive ability. This belief indicates that although M19 did not prioritise training her child to walk, she realised the value that society assigned to it. Although these mothers did not mention that this influenced their training plans, their beliefs might have affected the mothers' perceptions that the ability to walk was necessary for independence.

However, not all mothers prioritised walking; M12 stated that she did not prioritise her son's ability to walk, although the father did. Their child was able to walk using a walker, and he had mastered most self-care skills after training with his mother. The father was now training him to walk:

Mother: *'There are things I left for my husband to do, like walking; he sees that walking is the best thing'.*

Researcher: *'What about you? Where do you find the priority?'*

Mother: *'Because I want him to learn and go out into society, for walking he can move in the wheelchair or walker; walking alone is not necessary'.*

Researcher: *'You just said a few minutes before about speech – do you link it with independence?'*

Mother: *'Speech is the communication language, at least he can understand when he goes to a place how to buy and practice normal life; we always see people in wheelchairs. I told my husband they are fine not bad, but if he didn't learn or study this is bad, but my husband cares about walking, he said it is the first step'.*

Researcher: *'You mean he links walking and other things?'*

Mother: *'He said if he walks he will start mentally, there will be more space instead of being close, and the response will become better'.*

M12 first mentioned that she gave the father the responsibility of training their child to walk, as did several other mothers, mainly because of the physical effort required. Some mothers believed they

could not convince their children to train to walk, but they believed that the fathers were more firm and did not allow their child to slacken. M12 also said that instead of walking, she prioritised her child's education. This mother evaluated the skills in terms of how they would enable her child to engage in society, believing that an education would enable this more than his ability to walk. However, she also talked about the father's belief that walking should be a priority because it stimulated the learning of other skills.

M13 expressed a similar priority to have her daughter understand, rather than walk without understanding: '*Although she would be able to walk to the toilet instead of me carrying her, she would not be able to distinguish between the toilet and the living room.*' She stressed the value of understanding. M12 and M13 agreed with some other mothers in prioritising their children's cognitive development over the ability to walk.

Most of the mothers talked about their children's ability to walk and the value they placed on it. They referred to their belief in the importance of walking for the development of independence, stating that it would encourage the learning of self-care skills or improve the child's social skills.

As well as this, they recognised the value that society placed on the ability to walk, which could indicate the value that they themselves placed on the ability to walk. Several mothers said that although they

realised the value of the ability to walk, they prioritised their children's cognitive abilities. This finding is discussed in the following section.

6.1.4 Beliefs in the priority of independence

Some mothers prioritised skills that would enable their children to be independent; each mother's beliefs were shaped regarding priority by their background and understanding of their child's disability. For instance, data showed that some mothers prioritised developing their children's social skills, some prioritised walking and speech abilities, and others focused on developing self-care skills and preparing their children for future separation from them.

The data also revealed that some mothers measured their children achievements according to milestones. For instance, M17's son with mild cerebral palsy could walk with assistance, but had not yet completely mastered all the self-care skills. When he was young, M17 prioritised his achievements according to milestones:

> '*Before, when he was younger, I would think about his movement, and it was my concern. Now I want him to carry himself, to support himself. I want him to live independently*'.

M17 said that when her child was younger, she focused on his movements and transferring the mobility skills of crawling and walking. When he was older, she wanted him to master the advanced skills so that he could '*carry himself [and] support himself*'. This expression was used by other mothers, and refers directly to the child's independence.

‘Self-care’ translated to Arabic can be back-translated as ‘serve himself’. Therefore, the mothers’ use of this expression may indicate that they referred to self-care skills. In the above quotation, M17 prioritised the skills she believed were expected at a certain age. She believed that mobility skills should precede self-care skills, following what she believed to be normal child development. It is not surprising that the mothers had different priorities for each stage of their children’s development. This finding was especially evident in the responses of M19, who said that she started toilet training her child at the same age as normally-developing children. This indicates that the child’s age or achievement milestones influenced her decisions to prioritise an aspect of her son’s development. For example, M19 said the following:

> ‘*When he became three years old, I started training him on the toilet, I wouldn’t lose anything. His older sister, Lama (may God protect her), is independent and all. I was in Al-Ahsa at the time, so I said let me concentrate on him ... I only have this, so let me use my time on training him. I started training him on the bathroom. I spent, spent, and spent a month until he got accustomed to it. It took him a month exactly, thank God.’*

M19 mentioned that she started toilet training her child when he was three years old, at the same age as his able-bodied older sister. This mother employed the same milestone as a normally-growing child in her decision to start training her disabled child. This finding showed that milestones in child development might help some mothers in making

their decisions about training their children and in shaping their expectations regarding their children's ability to be independent.

Most of the mothers in the sample prioritised what they believed were their children's weaker skills more than other skills where progress had been made. M1, M6, M9, M10, and others whose children had already mastered walking, prioritised other aspects of independence, such as understanding, self-care, and education. Although these children had mastered walking – albeit with poor balance, which still called for frequent training – some mothers focused on the next skill rather than on improving the quality of the child's walking.

The findings also showed that the mothers' priorities sometimes depended on their focus. Some focused on abilities or skills their child needed at the time, while some focused on preparing for the future. For instance, M1's child walked with assistance, but he still could not eat, dress, or go to the toilet by himself. Focused on the long term, M1 was preparing the child for the future. When I asked her what she thought about regarding her child's independence, she said:

> '*Serve himself, serve himself, because I don't know how long I am going to live for him and want him to serve himself … in eating, in toileting, in sleeping. Not like now; he keeps playing in the living room [then] wants me to take him to sleep'*.

As explained previously, some mothers linked their priority of developing independence with their presence around the child. M1 focused on her son's mastery of self-care skills, linking its importance with her absence in the future. In the interviews, it was notable that the mothers mainly linked their children's self-care with their presence; some mothers did not prioritise self-care skills if they believed they would be able to continue to care for their children. In contrast, M5's priorities depended on her thoughts about her child at the time, and she was motivated by the child's desires. M5's son, with moderate cerebral palsy, still crawled, had poor speech and had not yet mastered any self-care skills. When I asked his mother what she thought about his independence, she said that she prioritised walking and speech over self-care because she linked these skills with her child's social abilities, and she believed that she was able to fulfil her child's self-care needs. She wanted her child to be able to play with other children:

> Researcher: *'What is the most important thing that pops to your mind when I say "independence"? Talk to me about this in detail'.*
>
> Mother: *'That he can take care of himself. And currently, currently, currently, I want him to be independent in speaking and walking; this is what I wish for. Regarding eating and dressing, it can happen later'. Because if he was able to walk his psychological state would improve because he will go, play, and talk with other kids; I'm speaking about speech and walking now. For eating and dressing up, it can happen later*

because he believes that he will eat and dress up either now or later, and he can learn how to do it later, like he learned how to walk and speak. Personally, I believe speaking and walking are more important because I want him to have social relationships. The kids will leave him because he is sitting in a wheelchair and he wants to go with them; they will climb the stairs, they will play on the roof of the house, and he wants to follow them but he is not able to. He calls them because he can't go with them. When I see him like this I want him to walk and speak more than seeing him eating, drinking, or dressing up by himself, so that his psychological state improves.

Although similar to M1, M5 said that she interpreted independence as 'taking care of himself'; she did not prioritise training him in functional skills to achieve independence. Rather, she prioritised what she believed would improve her child's mental health, which corresponded with his desire to master walking and speaking, to be able to socialise with other children and enjoy his childhood. The findings showed that on one hand, M5 focused on improving her child's social life, and wanted to improve the skills that she believed would enable him to engage in social relations and benefit his mental health. On the other hand, although she believed that mastering self-care would improve his independence, elsewhere in the interviewing process she also mentioned that as long as she was present, she would be responsible for his self-care. These findings, therefore, suggest that this mother

prioritised these skills as short-term targets. She did not link her child's current desires and mental health with his future needs. When the mother said 'personally', she wanted to send the message that her beliefs were specifically linked to her child's case, which may have prevented her from discussing the reasons for her priorities any further.

M13 also appeared to be motivated by her child's wishes. Her daughter had not mastered walking or self-care, and her cognitive ability was poor. M13 believed that her child might have had a strong desire to walk:

> '*I really want to know if she wants to walk, because I see her happy when she is surrounded with children and [she] becomes sad when they run away and [she] can't follow them*'.

This mother expressed concern about knowing her child's desires, which indicates that they may have had a role in her prioritisation of functional skills. Although her child wanted to walk, M13 prioritised understanding and self-care instead:

> '*If anyone asks me what do you like, what do you prefer? I will say I prefer [her to] understand more, because if she walks without understanding she will not get any benefit from this, imagine a person walking without knowing his way and where to go*'.

M13 tried to explain her belief in the importance of focusing first on improving her child's understanding. She believed that understanding would allow her daughter to benefit from the other skills, but if the child lacked understanding, mastering other skills would be difficult. She also focused on hand function:

> '*I didn't look for walking, I looked for hands, she will need her hands to move objects, to comb her hair to dress. If she understands and [her] hands are ok she will use her hands, but if she doesn't understand she will not know what these hands are and how we use them*'.

M13 also paid attention to improving her child's hand function so that she could practice self-care skills. However, she also believed that her child's understanding was a prerequisite to learning hand function and mastering self-care skills, which suggests that she prioritised independent thought over independent function. The finding also suggests that some mothers might have prioritised some skills over others because they believed they were necessary for learning the next skill. Although M13 said that her child '*will know how to walk*', in the two interviews, she did not convey the sense that she was optimistic about her child's improvement in walking skills, and her pessimism may have led her to focus on the abilities that she believed would improve. However, this is not to deny that the mother believed in prioritising her child's understanding as a gateway to mastering other skills. When asked about prioritising independence, M8 responded, '*I focus on*

understanding, then walking, then speech, then self-care'. In contrast, M15 prioritised walking over speech.

These findings showed that the mothers' beliefs influenced their prioritisation of certain functional skills over others. The reasons for their priorities included milestones, weak skills, and the child's wishes, as well as whether the mother was training her child for the present or for the future. In addition, some mothers believed that a certain skill was a prerequisite for learning other skills. However, the mothers differed in their prioritisation of their child's independence, which suggests that it would be difficult to identify a standard pattern in their prioritisation of independence skills according to their beliefs. Despite this, analysing and understanding the reasons for the mothers' priorities could provide more knowledge about the mothers' beliefs about training, and therefore more understanding about their beliefs regarding their children's independence.

6.2 Beliefs in their child's functional abilities

This theme concerns the mothers' beliefs about their children's functional abilities. The findings revealed that these convictions were linked with their thoughts about their children's ability to be independent. The beliefs were identified in the mothers' statements about their children's health status and different aspects of their children's abilities that were represented by their mastery of skills. The majority of the mothers talked about what they expected within the

boundaries of their children's abilities, as they were usually linked with their children's level of independence. This theme can be divided into two subthemes:

1) 'Expectations regarding child abilities', which demonstrated the mothers' beliefs regarding their children's ability to respond, their progress in independence training, and the likelihood of them continuing to develop in the future;

2) 'Supporting child's ability', which concerns the occasions on which the mothers realised that their children's ability needed to be supported.

6.2.1 Expectations regarding child abilities

In the interviews, when they were speaking about their children's abilities, the majority of the mothers discussed several areas concerning their expectations of their children's abilities. In this subtheme, the mothers' expectations are categorised into four codes:

1) Pushing the child within his or her current abilities;

2) Believing in his or her gradual development,

3) His or her developmental ceiling, and

4) Unexpected mastery of skills. The findings within these codes revealed the mothers' expectations regarding their children's abilities.

Pushing the child within current abilities

Many mothers used the expressions ‘push him or her’ or ‘within his or her abilities’, which indicated that they believed in pushing the child within his or her current abilities. These mothers believed they could identify their children’s abilities and push them to improve because they expected them to be able to develop them.

In the interviews, many of the mothers mentioned – frequently – that when they knew that their children ‘could use a skill’, they would ‘push’ them to use it. One example of this relates to M11’s child, who had moderate cerebral palsy and was in a wheelchair. M11 talked about their daily routine and indicated her beliefs about pushing him within his abilities:

> *There are things that are within his abilities; I try to support his self-esteem in them so he won’t fail; there are things I try my best at home to support him to do, that you should try. You can, even in, for example, dressing at the bathroom or eating, he is a little lazy, I try to tell him he can. For example, opening the yogurt; he asked me that day to open it but I told him he should focus and open it without spilling.*

M11 believed that developing her son in this way would support his self-esteem, and encouraged him to practice the skills that he was able to develop, even with difficulty. This mother also mentioned that she did not respond to her child when he asked for support. She expected her

child to respond to the training as long as it was within his abilities, and she believed in pushing him within this range. M11 also emphasised that children should be pushed within their abilities and that attempts should be made to avoid frustrating them. M19 agreed with M11 about pushing children within their abilities. She believed that as long as a child's hands were normal, they should be used to their full capacity. She said that when she asked her child to bring her a glass of water, she usually would not accept it if water was spilling out of the glass. She said that if her son was able to hold the glass firmly, he should always do so. This mother pushed her child to perform the skills well because she believed that he was capable. These findings suggested that some mothers believed that their children could achieve independence if they required them to learn and perform skills and tasks to the best of their ability.

M12 was in agreement with M11 and M19. Her son was at the stage of learning self-care skills, and she was pushing him to develop his abilities:

> *'Me and his father worked hard on this; I mean, we try to know anything he can do by himself, that's it, for example he can hold the apple, then he will hold it alone, then we try something harder, every time I ask him to go and do it alone, you have to brush your teeth. There are things he cannot do; no we don't push [him]'.*

M12 stated that she first focused on recognising her child's abilities – 'things that he can do by himself'– and pushed him to do them independently. She then mentioned that they would try harder skills to see whether he was capable of doing them. If so, she would continue to push him. However, she would stop pushing if the skill was beyond him. In another interview, M12 talked about pushing her child to practice his skills:

> Researcher: *'How do you act regarding the skills that he did not yet master, or you are not sure if it is mastered or not?'*
>
> Mother: *'I leave him to depend on himself, depending on the skill. For example in eating because I know he knows, I don't help him any more, he eats the soup by himself, takes the bread, cuts it; he takes things by himself, he doesn't need me; even if he asks for help I will refuse. I told him, "no sweetheart you have to take it yourself" but if there are things I know are hard for him, no'.*

Although the question was about the skills that her child had not yet mastered, M12 talked about pushing him to practice the skills that she was sure that he had mastered because it would ensure his progress. This finding suggests that her son might have been used to depending on the skills he had already mastered, and the mother was now pushing him to do these skills independently. She also mentioned that she would not ask him to perform harder skills and that she was pushing him according to her expectations of his ability.

These findings show how some mothers in the sample dealt with their children who had the ability to master skills. They believed that they could help their children to gain independence. It is understandable that the mother's capacity to identify her child's ability was necessary in order for her to push him to develop within his abilities. Furthermore, these findings indicate that some mothers knew when it was appropriate to pressure their children to develop a skill without eliciting a negative reaction because they had pushed them too far. The mothers who focused on developing their son or daughter within their abilities could identify their current ability and recognise their potential to be independent.

Gradual development

The findings showed that several mothers believed in the gradual development of their children, accepting a slow improvement in their children's functional skills. Moreover, they did not evaluate the possibility of their children's future improvement according to the current rate of progress, and accepted their children's current rate of progress.

For example, M6's son had already mastered walking with assistance. On the subject of training him to walk, she said:

> '*Now he is using the walker and I am planning to remove it but not all at once; first I let him walk holding the wall and house furniture, then slowly remove it*'.

This finding indicates that she realised that her child needed time to master each skill gradually, and that she enabled him to progress accordingly. The findings showed that if some of the mothers realised that mastering a skill required time, they accepted gradual levels of improvement to achieve the optimum development. This acceptance might have been reflected in M6's training of her child. Moreover, it probably increased her patience, so she avoided making early decisions about her son's ability, which increased his chances of achieving independence in the future. The belief in gradual development indicated that the mother expected her child to become independent. In addition, this expectation influenced the mother's training of her child and the number of opportunities she gave him to develop independence.

Developmental ceiling

The findings also revealed that although all of the mothers worked to train their children to develop independence, some of them believed in a developmental ceiling; that is, they believed that their children would reach a certain level of development beyond which they would not progress.

For example, although M12's son walked with assistance, he had learned most self-care skills and was still working at them. His mother described his training and abilities, and her thoughts about some skills:

> Mother: '*There are things I am convinced that he will never master'.*
>
> Researcher: '*How? Tell me more'.*
>
> Mother: '*The child … in his status won't be able to master everything impossible, but there are things we try to find, to encourage [him], and other things he can't [do]. I ignore them'.*

M12 tried to convey the sense that she was being realistic. She emphasized her belief that her child had limitations in mastering some skills, and justified this by mentioning another conviction, that these limitations were due to his disability. She acknowledged that there are some areas in which he could develop, while understanding the difficulty of development in another area. This can be interpreted as the mother believing that her child had a ceiling on his development due to his disability rather than the amount of effort put into his training programs. This provides insight into the mothers' expectations regarding their children's ability to be independent.

M3's daughter was still in a wheelchair, and she had not yet fully mastered any self-care skills. She had shown little improvement in

eating, and her mother did not train her regularly in most skills, although she showed the desire to learn to eat and dress herself:

> Mother*: 'When we go out to walk, I go to my family house walking; its near. I push her wheelchair sometimes, she said, "no I want to walk like you", I said, "I can't daughter, it's difficult to walk like us", she is giving me a hard time about this'.*
>
> Researcher*: 'You feel she is excited to walk?'*
>
> Mother: *'She is excited, but I depress her'.*
>
> Researcher: *'Depress her?'*
>
> Mother: *'Because I feel she is not able, and won't be able'.*
>
> Researcher: *'Tell me what makes you think that this skill or any other skill; walking, eating, dressing, will not improve?'*
>
> Mother: *'I don't know. I just feel that she stopped in a certain level and she won't improve, she is at the same level of development. I mean to say the girl develops, but I teach her how to dress, every time I sit with her and teach her how to enter her hand [into her clothes] and so on. She is not improving enough; just a little, maybe five percent, even in her eating'.*

The findings discussed in the previous section showed that because their children had the desire to walk, some mothers prioritised this skill. In contrast, M3 mentioned that although she knew that her child wanted to walk, she was reluctant to train her because she believed that she had reached her developmental ceiling. However, the findings also revealed that M3 provided physical therapy sessions for her child, which included training in walking, so the mother might not have actually been sure about her own belief in a developmental ceiling. M3 also refused to hold her daughter and encouraged her to walk, which might have been due to the mother's physical health, as she mentioned at another point in the interview. In the previous conversation with the mother, it was implied that the slow rate of her child's progress was the reason that M3 believed that her child was not able to continue to improve. She also mentioned that when her daughter attempted to dress or eat, she would not let her because she believed she was not doing it correctly, and she did not expect her to improve with practice. Therefore, the mother's conclusion that her daughter had reached a developmental ceiling was not based on the child's response but rather on her evaluation of her daughter's rate of progress. The analysis and interpretation of the mother's conviction that her child had reached a developmental ceiling contributes to an understanding of her beliefs about her child's independence.

Unexpected mastery of skills

In relation to this, some mothers believed that even though their child showed no signs of developing, they might suddenly improve without any previous indication of progress. For instance, M10's son was walking with assistance. She said that her belief was based on the sudden improvements that he had made in the early stages:

> Mother: *'It sometimes surprises me; that I don't teach him something but he does it'.*
>
> Researcher: *'How?'*
>
> Mother: *'For example before, when I was pregnant I was thinking about the new baby, how am I going to cope, and (child's name) still not crawling or walking; and then suddenly he crawled! I didn't train [him] I swear to God I didn't train, didn't teach, we were relaxing in the living room when that happened.'*

This mother expressed her belief that a skill could be mastered without any previous training, referring to a particular experience in which this sudden mastery had occurred. This finding reflects the mother's belief that her child's current developmental level did not indicate his developmental capacity. She did not find it unlikely that the same thing might occur in the future, as she believed in miracles and in God's will. This belief probably came from her deep faith in God's will and power, because she later mentioned that she expected another sudden

improvement to happen, which strongly suggests that she did not believe the first occurrence to be an exception.

The previous mothers' beliefs reflected their expectations of their children's abilities. That the mothers pushed their children according to their abilities indicated that these mothers were able to evaluate their children. They expected that the children would respond actively, and accepted their gradual improvement, as was revealed by their patience in training them. The mothers' beliefs in a developmental ceiling were also manifested in their expectations of their children's ability to improve. In contrast to that, some mothers believed that sudden improvements could occur in their children. These expectations might have influenced the mothers' beliefs regarding their children's potential and therefore their current training and future plans to develop their children's independence.

6.2.2 Supporting child's ability

One aspect linked with the mothers' beliefs about their children's abilities was supporting their children. Some mothers believed that their children sometimes needed help, and spoke about these occasions when they decided to support their children. The findings in this theme were drawn from the mothers' statements about helping their children by doing the task for them, or helping them undertake the task.

Avoid becoming angry

Some of these mothers decided to help their children in order to *avoid becoming angry with the child*. For instance, M16's daughter needed assistance with walking and had not fully mastered all self-care skills. M16 said that she did not allow her to practice being independent in order to avoid becoming angry:

> *Mother:* 'I used to not give her the chance to prepare her food or do anything for herself, but I was surprised that she made herself a sandwich; that day I was happy.*'*
>
> *Researcher:* 'That happened lately?*'*
>
> *Mother:* 'Yes it was surprising, I was thinking she doesn't know how, I mean I'm afraid that you know when the mother trains her child and he or she doesn't know how, she will get angry, specially after hard work every day and there is no benefit, then get angry, and I don't want to be angry and hit her'.

In regard to her statement about hitting the child, it is important to note here that according to Saudi Arabian law, a mother hitting her child without causing physical damage is not considered physical abuse.

M16 preferred to support her daughter in doing the task to avoid becoming angry when she tried but failed. She avoided training because she emphasised her relationship with her daughter and her mental health rather than the mastery of skills. The mother preferred to

accept her child's current level of ability and to support her rather than train her or let her try. M16's comment, '*I was thinking she doesn't know*', indicates that she was not sure of her daughter's abilities, which might justify her expectation that her child would not respond or understand her guidance.

Protect them from being angry

Some mothers talked about helping their children to *protect them from being angry*. For example, M18 helped her child to prevent him from becoming angry and frustrated. M18's son, with mild cerebral palsy, had mastered most of the self-care skills; however, she helped him to get dressed:

> '*If I came and asked him to wear his socks, gave him the socks, and say "put them on" then he started to insert it, his hand closed very quickly then he kept trying and couldn't, then became angry and frustrated and started screaming, then I did it for him and that's it*'

M18 was either protecting her child psychologically because she either felt pity for him and his difficulties or she wanted to reduce his efforts in training to avoid upsetting him. Regardless, she seems to have prioritised his mental health over developing his ability to be independent, which related to her belief about his potential to be independent. Similarly to M18, M6 supported her child in response to his anger. However, she did this to *avoid his fights with his siblings* when they finished dressing before he did:

'I came and found he did not do anything [did not dress] I became very angry and wanted to punish him, I went down and said that if you do not finish I'll go and leave you, although it is impossible that I do that. Then I went to him and asked him, "why were you angry?" he said, "because (sister name) and (brother name) go down before me". He wants to be with them. Then I called them and helped [him] dress and then they went down together'.

At first, M6 wanted to be firm with the child by asking him to finish dressing on time, which suggests that she expected him to be able to dress himself. Then she appeared to have some sympathy for him when he told her about his desire to join his siblings, and she helped him finish dressing. A similar scenario could occur involving a mother of normally-growing children of different ages with different abilities. However, in this case, M6 prioritised protecting her child psychologically, allowing him to carry out the task even though it would cause a delay. In addition, this finding could indicate that the mother valued her child's mental health over learning skills. Both M6 and M18 clearly expressed that they helped their children in order to avoid their frustration, even though they knew that their children could perform the task.

Child refusal

Many of the mothers who talked about supporting their children said that they would do the task for their children because they simply

refused to do it. For example, M12 and M17 said they helped their children because they refused to do the task alone and waited for someone to help. M12 said:

> '*He completely refuses to hold the trousers with his hands, he wants me to hold them, and change his clothes. I keep trying to ask him to do it repeatedly. I am not exaggerating when I say we take two to three hours or more to get him dressed; all that time to wear a shirt, trousers and socks*'.

It is possible that these mothers continued to support their children because either they lacked the time or they wanted to avoid tense relations with them.

It is not surprising that in general, the mothers in this study supported their children in carrying out their self-care skills during the day. However, some mothers talked about helping their children to undertake tasks. They described occasions on which they decided to help their children perform tasks that they had already mastered, or tasks that they were still learning to do. The findings suggested that these mothers supported their children to avoid becoming impatient because of their slow responses to guidance and training. Another reason was to protect the children psychologically by preventing them from becoming angry when they could not carry out the task in the same way that their siblings could. In addition, many mothers mentioned that they undertook tasks that their children refused to. Understanding these beliefs could reveal how they are linked not only

with the mothers' beliefs regarding the importance of their children developing independence, but also with the values they assign to supportive actions, which might affect their children's ability to master skills and achieve independence.

6.3 Conclusion

This chapter discussed the mothers' beliefs about their children's potential to be independent by examining two themes: the mothers' understanding of independence and their beliefs about their children's abilities. Although the findings showed that the mothers acknowledged the developmental abilities of their children, the findings in the first subtheme, 'mother's understanding of independence', showed how the mothers expressed their understanding of independence. It was found that the majority of the mothers valued the role of their children's level of understanding in their development to be independent, in terms of understanding the mother's guidance and being more aware of the surroundings. It was also shown that some mothers focused on the development of their children's personalities and they linked this with the children's ability to be independent in social interaction with other children and people. Moreover, it was found that most of the mothers encouraged walking training either to lessen the physical burden on themselves, or to encourage their child to interact and play with other children. One of the major findings was that there was no agreement between mothers on which area of their children's skills development they prioritised over another. The mothers prioritised what they believed their children needed to be independent, either their weakest skill, or

what they believed was expected according to developmental milestones. They were also found to prioritise self-care skills if they were focusing on separation from their child, walking if they were focusing on social interaction, or mental abilities if they believed them to have a role in other aspects of child development. In most cases the mothers priorities were reflected in their motives and focus on their children's training.

The mothers' beliefs regarding their children's potential to be independent were also examined through the theme of 'beliefs about the child's abilities'. This theme focused on what the mothers expected from their children's abilities, and when they decided that their abilities needed to be supported. The findings in this theme showed that most of the mothers in this study had expectations that their children could be independent. These expectations were revealed when the mothers talked about how they pushed their children to work within their abilities, their understanding of their children's gradual development of independence, the belief in a developmental ceiling, and in their children's sudden mastery of functional skills. This theme also revealed some mothers' beliefs in supporting their children's abilities, such as choosing to help their children perform tasks instead of allowing them to practice independence.

The findings that were put forward in this chapter showed that *understanding* the maternal beliefs regarding the children's *potential* to be independent is a step that precedes *identifying* the mothers' beliefs regarding their children's independence, most probably because of the

link between the child's abilities and independence. Findings concerning other maternal beliefs regarding independence training, will be discussed in the next chapter.

7 Chapter 7. Findings: Maternal beliefs in training their child towards independence

This chapter aims to explore mothers' beliefs regarding their children's training towards independence within the two interpretive themes 'mothers involvement in child training', and 'family members' role in child training', it will also analyse and interpret their articulation.

The diagram in Figure 7.1 below shows the interpretive theme 'beliefs in their child's training toward independence', and its relation to the other themes.

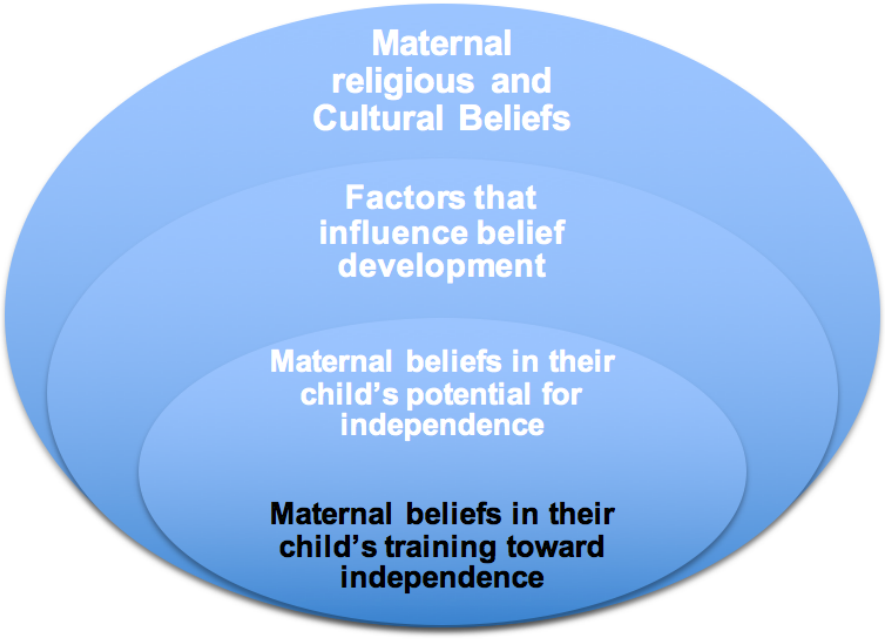


Figure 7.1. The 'beliefs in their child's training toward independence' theme and its relation to other themes.

This chapter can be divided into two themes with a number of identified subthemes that sit under the two main themes, as illustrated in Figure 7.2 below.

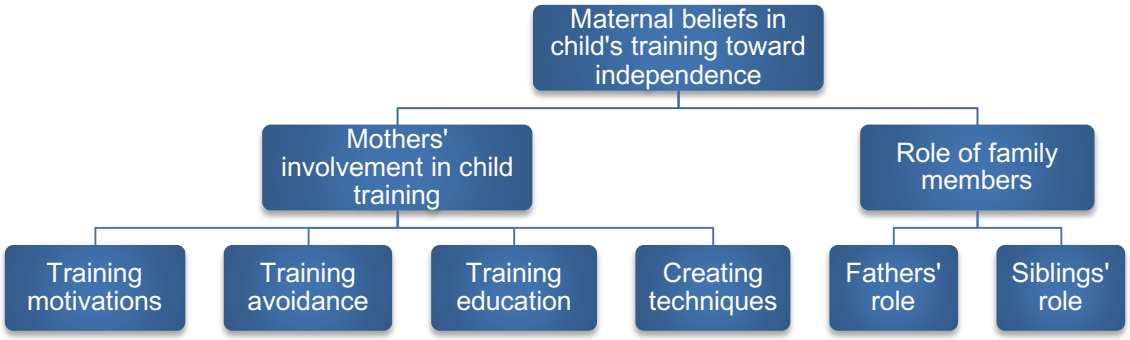


Figure 7.2. Subthemes of 'maternal beliefs in their child's training toward independence.

7.1 Mothers' involvement in their children's training

This subtheme will explore the mothers' beliefs about their own involvement in training plans for their children to become independent in their functional skills. Their training involvement included motivations, precautions, education, experience and the creation of techniques, as illustrated in Figure 7.2 above. This section will start with the most common and noticeable sub-theme, 'training motivation beliefs'.

7.1.1 Training motivation: separation and burden beliefs

Separation from the child

This theme will look at the two most common motivations behind the mothers' commitment to their children's training plans: separation from their children, and reduction of burden.

Most of the mothers mentioned their thoughts about separation from their children. They either talked about short-term separation, such as leaving the child for a few hours, or long-term separation in the future, although it should be noted that in Saudi culture adults never leave their parents' house before marriage and sometimes stay even after they get married. Some mothers mentioned their thoughts concerning what would happen to their children if they were to die. Others were motivated to train their children to be able to separate to enable independence, especially with children with mild cerebral palsy, in terms of cognitive and physical abilities.

For instance, M12's six-year-old son, with mild cerebral palsy had mastered most self-care skills, the last of which was toileting. M12 described her previous over-caring behaviour with her child and why she had changed it:

> '*When he was little we became very caring, and carried him. We over-cared for him (don't fall and things like that) and took care [of him] to [not] get sick. Now I've changed; when he falls I feel bad, but I say to myself, it is ok, he should depend on*

himself, I want him to start out on his own kick … Ok, the mental health of my child is important but it is not my target; my target is that he depends on himself. Frankly to be independent – I don't want him to be with me all the time. I want him to start out on his own life; he will be alone later. Am I right? We want him to reach this stage'.

In this extract the mother begins by talking about her son having a fall while she was away, and trying to explain that this should happen in preparation for separation. She emphasised her goal for her son's independence in terms of him depending on himself, and striking out on his own; even though she valued his mental health, his independence was her main concern. Indeed, she used the expression 'independence' in reference to separating from her child, which in this case was a short-term separation for a couple of hours.

Some mothers addressed separation directly or indirectly, referring to it as a symbolic indicator of independence. M17's seven-year-old son with mild cerebral palsy had not fully mastered most self-care skills such as dressing or toileting and did not have a satisfactory level of balance in walking. M17 stated that because her child was not yet independent, she could not leave him alone:

Mother: *'Outside the house, there are no problems, he can go alone, but it's very hard to leave him completely'.*

Researcher: *‘Talk to me in detail; why is it hard for you leave him? Talk to me about your relationship with him, and how you feel this will be reflected upon his independence?’*

Mother: *‘It's hard because I can't still place him at a level of independence that is satisfactory for me. I believe that the percentage of his independence is less that 50%. To say the least, he can't balance, and if he falls down, he crawls. You imagine, the kids walking, and he is crawling amidst them! I don't find the situation quite satisfactory; not quite – actually it’s not satisfactory at all!*

The mother began by contradicting herself, mentioning that although her child could be left alone she continued to insist on supervising him. She said that her child’s poor independence was preventing her from separating from him. It was also realised that continuous accompaniment due to the fear of him falling was because of poor separation, not his self-care abilities.

This might be a motivation for the mother to train her son for balance so as to lessen her need to physically protect him, and thus increase her confidence to be separated from him.

Separation from the child was a common issue to talk about with the mothers, and the children’s poor functional abilities were often a reason to delay it. Although not always directly expressed, preparing the child to

be able to leave the maternal home can be a motivation to train a child to master the skills that enable independence.

Lessen the burden

On other occasions, the mothers talked about training their children because of their desire to remove some of the burden from themselves. Although this might refer to the mental health burden, when I asked her why she depended more on physiotherapy sessions than home therapy, M13 said '*Sometimes I say let me rest and let someone do it for her, and see what's new*'. Mothers mostly referred to the physical burden of carrying the child and helping with self-care skills. Some of the mothers mentioned that training their children would lessen their burden. M15's motivation for her child to learn how to walk was split between her desire for her child to be able to separate from her and her desire to lessen the burden on her. M15's six-year-old daughter, with moderate cerebral palsy, had not fully mastered her self-care skills, and moved using a wheelchair. The mother said, '*I want her to get up and go with her sisters and brothers and stop being around my neck all the time*'. The mother wanted her daughter to join her siblings, who were able to be separated from her, and emphasized her wish to reduce her own physical load. Few mothers talked indirectly about their children being a burden, yet most of them had large families and took care of the whole house in addition to being responsible for their disabled children. They perceived that their children would require more work as they grew up.

M13's seven-year–old daughter was not walking and had not mastered all her self-care skills. Talking about her child's training to walk, M13 mentioned that one of the benefits would be to lessen her own burden:

> '*I want her to walk, not only to release the burden on me and give me a little relief, but also for her. If she could walk, she could go to the toilet alone. I wouldn't have to carry her. She and I would both be relieved*'.

The mother here stated clearly that her daughter's mastery of walking would reduce her own workload, and would also help with her toilet training. She stressed that her child's improvement would be better for both of them, which might indicate that she wanted to emphasize that her desire for her daughter's independence was not selfish. On another occasion, when I asked her about her child's ability to crawl to the toilet to wash, and why she carried her, she said: '*as long as I can, I will carry her*'. This presents a contradiction: although she believed that her child's ability to be independent would reduce her burden and motivate her to train her daughter, at the same time she linked this with her physical ability to support her child and her role as a mother to take care of her. Although the mother earlier showed an interest in developing her daughter's walking ability, at the same time she might not have found crawling satisfactory for her daughter's mobility, which might in turn make her feel that part of her duty as a mother was to serve her child by carrying her.

As with many of the mothers, M2, when talking about her child's self-care skills, mentioned that she wanted him to walk, and referring to dressing and eating she said, '*it's ok I will do it for him*'. However, M2's child was not walking and had not yet mastered any self-care skills. Many mothers found that their children's self-care was not a burden, but walking was. This can be linked with the findings in the previous chapter that set out the mothers' understanding and prioritizing of independence. The mothers' feeling of being burdened regarding any of their children's limited skills, either mobility or self-care, would contribute to shaping their understanding of their children's independence and thus their prioritising.

Most of those who described their physical burden were the mothers of children with poor walking abilities, and they focused on training their children in walking, believing that mastering these skills would lessen their burden. On the other hand, the mothers who focused on separation from their child were primarily concerned about their children's self-care skills. Understanding this clarifies the mothers' reasons behind their desire to train their children to be independent, and therefore their beliefs regarding independence.

7.1.2 Training avoidance

The mothers mentioned that they avoided some training activities as part of the home programme, believing that they were best performed by professional physical therapists. This theme will illustrate some of

the convictions the mothers had that justified their avoidance of their children's training.

Fear of harm

Two mothers said that they avoided training their children because they feared harming them in some activities. M13's daughter, with moderate cerebral palsy, had poor mobility and stiff joints. Discussing her child's training sessions, and the home programme, the following emerged:

> Researcher: *'Do you have a home exercise programme from the centre?'*
>
> Mother: *'Yes, I brought a ball'.*
>
> Researcher: *'OK. You mean you are doing exercises at home?'*
>
> Mother: *'Because her muscles are tightened, I am afraid they would get dislocated or fractured. No matter how much you learn, they have a certain method. Sometimes I think about letting somebody help me and I would continue after him or her'.*

M13 believed that because she was not a professional, she did not have enough skills to train her child. She talked about her fear of harming her child, especially in exercising her stiff joints. M12's six-year-old son with mild cerebral palsy walked with assistance. In a

similar vein to M13, M12 mentioned that he was calmer during their home sessions (performed by the father or physical therapist), but when asked if she participated in these sessions, she said: '*I don't know how, and the therapist warned me that I might cut or harm a tendon, which would make things more difficult, and made me afraid of doing this thing*'. Both mothers believed in the expertise of the physical therapist and did not have the confidence to practice certain exercises with their children. Some activities, like standing and walking, or activities using a bouncing ball or stretching exercises, for instance, are painful if the muscles are tight and this can distress the children, at times making them cry. This causes the mothers to lose confidence during training, increases their desire to protect their children, and reaffirms the belief that they might harm them.

Child refusal

In some cases, the child may refuse to respond to the mother's training, and consequently the mother does not push them. M2's son, with moderate cerebral palsy, had not yet mastered walking or self-care skills. Asked about her home training with him, M2 said that she did not train her child to walk while he was undertaking walking training at the centre:

> '*Here, they are strict with him, so he does what he is asked to do because he doesn't see me around. When he sees me, he gets spoiled and refuses to do anything I ask him to do. This*

also includes therapy; when I am with him, he refuses to do therapy, but when I am not, he does everything they ask him to do'.

The mother believed that her presence at the centre interfered with her child accepting the training, and this was even more pronounced at home. Because of this, she decided to give up, feeling that it was not one of her responsibilities. In both cases the mothers put more faith in the professionals' responsibility for training, and appear to have been flexible and passive in dealing with their children's refusal to train with them.

Hygiene concerns

Some of the mothers struggled to teach eating skills, either because of their children's slowness (if time was short) or because of tidiness and hygiene concerns. For example, M3's nine-year-old daughter, who had not mastered eating, kept trying to feed herself, but her mother could not tolerate her making a mess with food:

Mother: *'For example, I don't like her way of eating. She eats improperly. When you see her eating, she messes up everything around her'.*

Researcher: *'You don't feel that if you let her, she will learn with time?'*

Mother: *'Why wait for time! I want her to learn now, I try with her, why neglect her? Am I also supposed to wait for time?'*

The mother did not accept her child's level of performance in eating, which caused a mess, and appeared not to feel that this practice would help in developing her child's eating skills. Her concerns over tidiness and hygiene caused her to avoid training her daughter. At the same time, she seemed to be running out of patience waiting for her child to improve, and wanting immediate improvement. In the previous chapter, M3 was shown to be one of the mothers who did not accept gradual improvement; she said that she did not appreciate the slow improvement of her daughter's self-care skills. She preferred to have a clean place rather than trying to develop her child's eating skills.

M15 also said that she fed her child to prevent mess and keep her child from becoming dirty. Her daughter, with moderate cerebral palsy, was not walking and had poor mastery of self-care skills. This concern was repeated frequently by the mothers, which showed that having a messy home was a concern they could not easily ignore, especially since their children might have practiced eating several times a day, adding to the mother's workload to keep the home clean. At the same time, while some of the mothers might have felt that letting their children practice eating freely would not delay their development of eating skills, the others might not have been very optimistic that their children would learn eating skills at this stage. The mothers' reluctance for their children to

practice eating indicates that there are circumstances in the children's routine in which the mothers prioritise hygiene and tidiness while not undertaking training.

Prevent child anger

M16 said that she avoided training her child to prevent her child from getting mad at her. Her six-year-old, daughter with mild cerebral palsy had not fully mastered her self-care skills:

> '*I am afraid to train her because if I put in hard work every day and do not get good results, she will get mad. She will get mad, which might make me react angrily and hit her. I would rather avoid the situation, and even though she has a delay in everything, I say to myself she will develop'*.

Although at the end of her explanation the mother expressed optimism that her child would develop, her avoidance of training was due to her low expectations that her child would actively respond to her training and improve. She also doubted her ability to control her anger, and she chose not to train her to avoid getting upset and angry. The mother appears to care more about her relationship with her child than her daughter's chance to develop, which could point towards the mother's beliefs in her own efficacy in training.

Few mothers actively talked about avoiding training their children, but it is worth noting that some of them mentioned these points without being directly questioned about their training. Understanding this provided more insight into the mothers' beliefs regarding their roles in training their children to be independent, and the value they gave to home training, as well as the potential for avoidance of child training and the possible reasons behind it. Beliefs like fear of harm, prioritising tidiness, or their relationship with their children could have outweighed their belief in the importance of the continuous training of their children.

7.1.3 Mothers' training education

This theme is concerned with the way the mothers learned and developed their knowledge to enhance their efforts in training their children to be independent.

Learn during therapy session

Although educational classes for the mothers to learn how to train their children were not provided by the centre, the majority of them mentioned that they believed that they could learn how to exercise their children through watching the physical therapy sessions, and receiving clarification from the therapist. M12's son was training in walking and balance. M12 talked about him training at the hospital and sometimes at home:

> Researcher: *'Do you see that your husband's training and the therapist's training are the same?'*

> Mother: *'Exactly the same; he basically learned from them how to do it, but (child name) is taking some sessions there because the father is not always free – you know he comes back tired also from work*'.

The mother specifically mentions that the father, who was usually responsible for training the child, derives his knowledge from the physical therapist. It is pertinent that M12 was one of the mothers who avoided training her child because of the fear of harm.

M7 also talked about learning exercises from the physical therapist. Her child has mild cerebral palsy, and most of the walking training was performed by her at home:

> '*Of course the therapist is better than me, but she can give me the exercises. I go with my child and watch, and she shows me, "we do here like this, and think this". I find them helpful*'.

The mothers mostly talked about regular exercises focused on mobility skills that linked standing and walking, more than self-care skill. on the other hand, one mother (M12) talked about consulting a psychiatrist about their children's struggles with toilet training, her son is six years old, and has mild cerebral palsy. She said: *''First we tried encouraging him, punishing, everything you want, because he took a long time to master toileting. He tires us in this training, [we] thought of everything, and the psychiatrist here helped us, she put it down with paper and pen*

and I had a belief that he has to learn this'. Although M12 narrated her own experiences in training her child in toileting, she had asked for professional help to guide her in the training.

Self learning

Many mothers said that when they needed information, they immediately went to the Internet; one of the mothers talked about educating herself by watching videos, M1, whose child has mild cerebral palsy was doing most of the training at home, along with the father. She said:

> '*I teach him to walk at home. From an early age, we addressed walking by watching tutorials on YouTube. We also got the balance ball we saw on YouTube and gave him different exercises to strengthen his back'*.

These mothers did not wait for the professionals to impart their knowledge, but made an effort to gather the information they needed to understand their children's status, learn training activities and read success stories. The mothers used several sources, for example YouTube videos. This is believed to be a notable step for those mothers who want to overcome the limited information available in Arabic texts over the Internet by watching videos that demonstrate how to practice the exercises. This also reflects the mothers' efforts to make their training more effective.

Many of the mothers mentioned one or more ways in which they educated themselves. When the mothers sought out opportunities for education or information, it emphasized the amount of care they took to enrich their knowledge about training their children to be independent. It also highlighted the value they placed on their role in training them, which in turn revealed a greater understanding of the mothers' beliefs regarding independence.

7.1.4 Creating techniques

When the mothers were explaining their daily routines with their children and their contributions to the process of training their children, they talked about how they created techniques that they believed were effective in specific training areas. Understanding these techniques might provide knowledge about the areas the mothers believe are worthy of effort and want their children to be trained in, as well as about their beliefs regarding their own roles in training their children to be independent.

Storytelling

One technique that was believed by two of the mothers to be different and effective was storytelling to develop a skill or to control behaviour. M6 explained how she taught her seven-year-old son a task, or 'fixed' some of his behaviour – for example what she perceived as stubbornness – by telling him a story:

Mother: 'If I want to fix something with him I do it with a story'.

Researcher: 'Talk to me about this point more'.

Mother: 'I bring a story, I mean, I pick a suitable story from my mind about a boy who did so and so and he listens to his mother and when he grows up so and so happened; using stories for therapy is amazing; story as a style for therapy is amazing'.

The mother expressed her admiration for this way of dealing with her son's behaviours or skills. M8 also employed the same technique. Her nine–year-old son, with mild cerebral palsy, used to imitate, so she got his teacher to use storytelling in training him to master skills:

Researcher: *'You just mentioned that you use stories in training?'*

Mother: *'Yes'.*

Researcher: *'Talk to me more about this point, please'.*

Mother: *'Most of the times he likes to imitate, so we give him stories'.*

Researcher: *'OK'.*

Mother: *'And there is a good thing, that he imitated the one in the story in the toilet thing, we started the story – the teachers helped me – he was doing it on him self, so when they started*

to tell the story about a clean boy who used the toilet, thanks God this was it and this thing was done and we forgot that he was doing it on himself because he started to imitate the story'.

When the mother realised her child's tendency to learn from imitating, she told him stories employing the 'good boy' model. In her example, this 'good boy' was the child's model to learn and master toileting. The mother was trying to make the child acquire or learn new behaviours and skills by convincing him of the model of the 'good boy'. This means that the mothers believed that influencing their children's self-belief, and how to be a 'good boy', played a role in developing their skills. This might also point to the mothers believing that the children share their own process of training for development. Understanding the mothers' application of this technique provided information about how some of them can be creative in using different methods to train their children, about their beliefs in how independence can be achieved, what skills should be focused on, and their role in the training.

Learning styles

The mothers also used different learning styles to teach their children tasks, according to what they believed was effective with their children (Gardner, 2011). Most of them believed that their children responded to verbal instruction, mainly linking it with their level of understanding, as demonstrated in the previous chapter (see Chapter 6, Section [6.2.1.1]. In

some cases they believed it would improve their children's understanding. The mothers would articulate and describe the instructions verbally for their children, and expect them to understand and respond. Other mothers believed their children responded to a visual learning style, where they demonstrated the task to the children, showing them how to perform it in line with their ability to see and register the images. Only a few mothers believed in a kinetic learning style, in which the part of the child's body responsible for the skill is held and moved according to the task. M13 described how she taught her daughter how to eat in the early stages when she was only receiving food by a tube. She mentioned that she used to put pieces of food inside her child's mouth, moving her jaw with her hand and demonstrating chewing for her visually at the same time; she believed this was the only effective way to teach her how to eat. M1 believed that her nine-year-old son, with mild cerebral palsy, responded more if she talked and demonstrated the skill at the same time:

> Researcher: *'You just told me about repetition, I want to know what is your way in guiding her?'*
>
> Mother: *'You mean how I teach her?'*
>
> Researcher: *'Yes'.*
>
> Mother: *'I show her and talk to her, then she copies me, she understand me, she hears me while am talking and watches while I am doing it, so she can copy the same way I do'*.

The mother mixed verbal and visual learning styles because she believed in her child's ability to see and to understand, which was sufficient for her to be able to copy the task and learn it.

M2's seven-year-old son, with moderate cerebral palsy, moved using a wheelchair and had not yet mastered his self-care skills. Although his mother did not prioritise teaching him self-care skills, when she was training him, she thought that he responded more to visual guidance:

> Researcher: *'When you want to train him for a specific skill, how do you do this?'*
>
> Mother: *'Mostly I bring the thing in front of him and do it, to [show him] how to do it, so he can do it after me'.*
>
> Researcher: *'Why did you choose this way over telling him or doing it for him before?'*
>
> Mother: *'To excite him, and confirm it in his mind, and get him excited because he saw me doing it and wants to do it like me*.

Although in this extract M2 mentions her son's high level of understanding (see Chapter 6, Section [6.2.1.1]), she does not link this to her choice of learning style, believing a visual learning style to be more effective and exciting for her child to learn. Comprehending how the mothers teach their children independence might help in understanding how they link their knowledge regarding their children's abilities and the learning style

they apply, and this can provide more information about how they believe independence can be achieved.

Instruction repetition

Some of the mothers mentioned that they believed that repetition improved their children's understanding and so would repeat instructions to them. This might also be linked to the mothers' learning style; those who used repetition to improve their children's understanding preferred a verbal learning style to teach skills that enhanced their cognitive learning and their memories.

M15 and M6 also said that they used to repeat instructions or information for their children. They believed that their children needed to listen to the instructions several times in order to understand the process. Repeating instructions requires more time and communication, as well as greater adherence by the child. This training method shows that the mothers linked their children's ability to understand with the development of other skills, such as self-care or mobility. It also provides information about the mothers' beliefs regarding their commitment in training their children to be independent and how independence can be achieved.

Child continues task

Several mothers said that they would start a task for the child to continue, such as dressing. M16's daughter had not fully mastered her self-care

skills, but was in the process of developing them. M16, when talking about her daily routine, mentioned how she helped her get dressed:

> '*It is difficult for her to pull her pants up, so I pull them halfway up for her and then she continues. I watch her and intervene with difficult or tight clothing'*.

The mother was focusing on the whole process of her child getting dressed, choosing to do the hard part and getting her to continue. The decision about at what point she provided support shows that the mother was paying attention to her child's abilities and limitations and trying to improve her skills. From the interviews with the other mothers, it seems that they believed the initiation of the task to be the difficult part, so they started by guiding their children. This showed that the mothers focused on their children's level of independence, supported their needs and acknowledged their current ability, thereby promoting the development of independence in that particular skill.

Child encouragement

Moreover, while describing their interactions while training their children, most of the mothers spoke about how they encouraged their children during their application of the task or after they finished. M6's son walked with assistance and was in the process of mastering his self-care skills.

M6 paid attention to her child's training, and believed that the *encouragement role* was very important to motivate him:

> *'When he jumps on the trampoline I hold him and help him jump and tell him "your legs are improving because you are doing exercise and walking." I have to encourage him, or how he is going to know that he is improving then? I am doing so to encourage him in therapy time. I told him you are going to be good you are doing exercises very well even it hurts you I have to encourage him from the inside, he is the kind [of boy] who loves compliments and encouragement very much'*.

Here, the mother explains how she spoke positively to her son, how she acknowledged his efforts in exercising, and how she was optimistic about his future. She believed that he needed to be encouraged to improve and realised that he appreciated it. In saying that she tried to '*encourage him from the inside*', it appears that she wanted him to be convinced of the positive things that she told him about his abilities and future, as if his improvement was self-perpetuating. The mother therefore believed in the child's confidence regarding his abilities and his role in his own improvement. From this it can be understood that the mothers who use encouragement while training their children believe that their confidence in their abilities will be reflected in their performance and development, and in achieving independence. It also

indicates that these mothers believe that their children play a part in their own training process.

Tools to facilitate development

Several mothers talked about using tools to facilitate development or to attract their children to training; for example, M11 recommended that her son rode his bicycle to the closest grocery store instead of doing leg exercises at the hospital or home:

> '*He should regularly do exercises to strengthen his leg and back muscles. Now we are trying to make changes as we can. I bought him a bicycle, and I am trying to implement changes in physiotherapy training methods for him not to get bored. Just think of yourself when you do the same exercise everyday*'.

M11's child was still using a wheelchair, however, he was continuously training to walk. The mother used his bicycle as a tool to entice him to try practicing the task or to make it easier. The mother also introduced a mode of transportation that encouraged more independence than the wheelchair, revealing how she creatively encouraged her son's independence in his daily activities.

It is popular among mothers in Saudi Arabia to encourage their children by comparing them to their siblings. Therefore, it was not

surprising that they tried to motivate their children by using their siblings as examples of good practice, encouraging their children to complete the task by asking them to be like their brother or sister. M6, for instance, discussed how she approached her son's toilet training:

> *'For example, when he goes to the bathroom properly, I tell him he is a good boy, but when he excretes in the wrong place, I tell him he is not a good boy and say, "See, [sisters name] was a bad girl before, but now she is good. [brothers name] is now a little bit bad but will be good later." I always encourage him and play with him'.*

The mother used the siblings to encourage toilet training, putting her son in the category of 'not a good boy', and his sister, because she had mastered toileting, in the category of 'good girl'. The mother did not mention how she realised the general differences between her children's abilities and whether or not her son recognised his delay. The mother believed that giving an example of a sibling's achievement would motivate her son to achieve it as well. M6 focused on her child's personality, believing that in this way the child would be encouraged to learn how to do the task.

Demonstrating how the mothers created techniques to train their children provides information on how they believe independence can be achieved. It is also noteworthy that most of these techniques – storytelling, repetition of explanations, encouragement, a verbal

learning style and comparing them with their siblings – worked at the mental level of the children. This showed that the mothers believed in their children's role in their own training process, and they focused on making their children understand the tasks and convince them of their abilities.

The effort the mothers exerted in creating and practicing these techniques gives an indication of their priorities in developing independence, and their commitment to training their children.

7.2 Roles of family members

The mothers talked about family members' roles in their children's training. The phrase 'family members' in this case refers to the fathers or the siblings who live in the same house with the disabled children and see them on a daily basis. The mothers sometimes ask them for assistance and on other occasions, those family members help proactively. This section will explore the mothers' beliefs about the roles of the fathers and siblings in training their children, as well as the mothers' beliefs concerning how they can contribute to developing their independence.

7.2.1 Beliefs about fathers' role

As explained in the Methods section [3.3.5], there was no opportunity to meet with the fathers to explore their beliefs, so some of their beliefs have to be understood through the mothers' words. In this section, some of the

fathers' beliefs regarding training their children to be independent will be highlighted, but the focus will be on how the mothers viewed the fathers' role in the development of their children's independence, and this will be captured from the data. In the current sample, the fathers' support of the mothers varied from lacking to significant. However, the majority of the mothers believed in the importance of the fathers' role and appreciated their help, if it was provided. M1 agreed with the father in his son's training and believed he had a role:

> Researcher: *'How is his relationship with his father?'*
>
> Mother: *'He is so much attached to his father, and his father spoils him. We both follow the same strategies. He is proud of him, encourages him, and takes care of him. When [child's name] was younger, he used to buy him puzzles to help him focus.*
>
> Researcher: *'Does his father enhance his independence?'*
>
> Mother: *'He helps [him to] be independent, but keeps an eye on him. He gives him food and watches him while he is eating, or changes his clothes, but lets him button up; he watches him and teaches him, just like me'.*
>
> Researcher: *'Okay, what are his father's thoughts regarding his son's independence in the future?'*

Mother: *'It troubles him, just like it troubles me. He worries about his future and feels that if he teaches him these things, he will be able to be independent'*.

This mother expressed satisfaction with her child's relationship with his father, as well as the father's behaviour towards their son, noting that he 'spoiled' him. The word 'spoil' in Arabic is usually used to express care, love, and generosity, so the mother's use of this expression gives the impression that the father is kind, supportive and giving. She felt supported, and shared the responsibilities with the father; they agreed on their strategies, as evidenced by her statements 'we both follow the same strategies' and 'just like me'. The mother appreciated the father's role in supervising their child and in self-care training as well as the father's beliefs regarding the importance of teaching their child skills to develop independence.

M6 also found the father to be supportive:

'Their father always plays with them. He does more than all the things I do for them combined. They play hide and seek. He always tells (child name) "you are a man and you are like your father". We share the same beliefs regarding (child name)'s condition, thank God; he believes we shouldn't be ashamed of him and he should go out everywhere like any normal kid. He would like to see (child name) using the bathroom by himself, but is too busy … Once, my husband took (child name) with

him to a wedding and they were wearing traditional thobe, hat, and bisht [traditional garb]. When they went out of the wedding, a man told my husband: "How do you bring (child's name) to a public place!?" My husband told him there is nothing wrong about bringing him, "why shouldn't I!?"

The mother stresses her agreement with the father regarding their child's condition, and his contribution in training the child despite being busy. The mother also highlighted the point that the father did not stigmatise his child's condition, especially considering that once the child reaches a certain age (12-14 years) as a 'boy' in Saudi Arabia he is segregated from women and interacts only with male society. This becomes a challenge for the father to support his child. In this case, the father was working to develop his child's social abilities and encourage him to participate in extended family gatherings as part of developing his social independence.

In some families, for example M12 and M15's, the father was in charge of physical and mobility training. When M12 was asked about the child training process, she said:

Mother: *'When he works all day I don't put more stress on him, if he [the son] walks for a while, that I feel it is enough, that's it, stop; let us give him a chance to relax. For example, if he doesn't want to walk in the walker he makes us carry him or it is ok for me if he crawls, but his dad refuses to [let him] crawl'.*

Researcher: *'Does his dad or you have more of a role in his independence training?'*

Mother: *'No no his father for sure; he is better than me, honestly'.*

Researcher: *'Please talk to me more about this point'.*

Mother: *'His father, God protect him, is a very hard worker in (child name)'s case. When I got pregnant again with my daughter I was afraid that this tragedy would repeat, that's why I stopped moving; then my husband was in charge of (child name) and he changed a lot of things for him, specially crying while doing physical therapy: even if he cries to death he has no problem – not like me; I used to stop the session when he cried too much, but his father said "it is ok, let him cry and cry he will get used to it and change it." He really changed. I was scared that he would ride the bicycle and fall but his father made him ride the bicycle, his father let him ride it and went out with him to walk and along the beach side and he considered it as physical therapy; for me, I can't do this*.

M12's husband was supportive, and she recognised his role in training their child. She described her flexibility in letting her child crawl, and her fear while training him, at the same time acknowledging the father's support, which started when she fell pregnant and her efforts were reduced. The mother believed that the father had a firm way of training

their child, and appeared to agree with his approach, realising that she was not able to reach his level of commitment and insistence. At the same time, she appreciated his significant role in training their child to be independent.

A number of mothers, on the other hand, talked about absentee fathers. Some of them were physically absent, such as the father of M4's children, who had been in prison and had just started seeing his family on a monthly basis less than a year before the interview. M4 did not complain about his absence, but during the interview it became clear that his absence required her to work longer hours and do more, and also caused her more stress. Although her child was still developing independence, the mother did not appear to be worried about enhancing her child's development. This was interpreted as the mother prioritising her added responsibilities and filling the gap left by the father over focusing on her child's improvement.

Some of the mothers, for example M7, M8 and M1, mentioned that the fathers were busy (at work, etc.), and did not have time for child training, so the responsibility for training the children fell upon them. A number of other mothers did not often mention their beliefs regarding the roles of the fathers in their children's development. M9 said that when she was training her young son to develop his vision after the physician had evaluated him as blind, the father did not support her in her training, believing she was wasting her time. He also told her that her efforts might interfere with his faith and acceptance of what God gave them, but despite this, she kept training her child alone until his vision developed.

This was one example of a mother having different beliefs to the father regarding her child's ability to develop.

M7, M18 and M17 mentioned that the fathers of their children quickly became agitated and they believed that they might be tough with their children, so they preferred them not to train the children. This might also be interpreted as psychological protection from the mother toward the child. M3 stated that the father rarely shared in their daughter's training, and believed that bringing a physical therapist home for training sessions was a waste of money because of her slow improvement:

> Mother: *'No, I told you I don't like to upset her. I don't want her to be upset. Because of her condition, I don't like anybody to upset her, including anybody – even her father. He was yelling that day, and upset me, we had a fight, and we almost got divorced because of her'.*
>
> Researcher: *'Why?'*
>
> Mother: *'See, the specialist I hired for her, her father said that I am wasting money, spending 200 riyals for a session that lasts for less than an hour. That's none of his business! It's my money, I didn't hire him with your money, I am paying him with my money! I work hard for her. Every penny I make is for her. I don't care!*'

This illustrates the father's beliefs about his child's progression and the negative effect that he could cause. In this case, the father's belief did not influence the child's rehabilitation plan because the mother was paying for the specialist. This account suggests that fathers may sometimes intervene when money is being spent on the child.

At the other extreme, some fathers denied their child's condition and the importance of focusing on their case, and refused to share in the responsibility. M10 said:

> *'I found a lot of difficulties, and the first one was my husband, he was thinking these trips to the hospital were useless effort and we would not achieve results. He told me a sentence once that broke my heart, he said "they are like experimental mice you are trying everything; just leave them at home – eat, drink, and sleep", but I said "sorry to this point no, leave me to be the one who becomes tired from going but does not sit and watch with crossed hands and then blame myself." To be frank my husband, until now, did not get over the shock of having disabled children and honestly is not helping me. I know I am talking behind him; his work also of having different shifts adds to him not being supportive. He did not do anything for them, I was the one who did everything'*.

The mother stated clearly that the father withdrew from any responsibility in training their child, expressing a deeply negative outlook about their

child's possible improvement. However, the mother did not give up, resisted the father's behaviours and beliefs and took responsibility for training their child to develop independence.

M2 also commented that she was responsible for all her child's hospital appointments, rehabilitation sessions and enrolment at the rehabilitation centre. She wished the father would take some of the responsibility: *'if his father was with him he would see some firmness; he would be scared of him, but me he is not afraid of me, I always laugh with him'*. Here, the mother sees the father's role as being firm, and believed that this behaviour influenced their child's training and development of independence, but was out of her hands. She also said:

> '*His father is ashamed of him; he doesn't take him anywhere with him. I am a woman; he needs his father to help him be a man from now; take [child's name] with him everywhere*'.

In this statement, besides feeling that the father was no help, the mother pointed to a cultural belief in the limitations of her abilities as a mother and that her son needs a father to imitate: '*I am a woman, he needs a father to help him to be a man*'. Although she stated that she was in charge of many things, she also expressed her limitations in some areas that were needed for her child's independence and believed the father was responsible for these. She also reported the father's belief that supporting self-care tasks was for women, which can also be considered a cultural belief.

M5's son, who has moderate cerebral palsy, used a wheelchair. His mother mentioned that the father agreed with her in how to treat and train him, but also spoke about an occasion when the father was angry about his side of the family's ignorance towards their child:

> Mother: *'The society, frankly, here … I mean I treat him as normal child, even my relatives from my mother's side and my uncles in the gathering they ask me to bring his walker so he is able to play, they treat him normally, God bless them, they help me, but my in-laws they see him as a wall [the father] comes to me very angry and shouts to me "take him", I asked him what happened, he replied "that's it. Take him with you!"*
>
> Researcher: *'You mean this in the Eid gathering?'*
>
> Mother: *'Yes in Eid days, I don't let him be with me, I want them to know him; he is old now.'*

In this extract, although the mother talks about the bad treatment the extended family gave her son, she also draws attention to the father's reaction when he had to bring his son with him to the male part of the social gathering where he became agitated because his family ignored her child. The mother seemed to understand the father's situation and anger and put the blame on society. This position of the father limits his role, especially if the child is a 'boy' and should be segregated from female society at a certain age. On the other hand, as mentioned in

previous examples, M6 and M19's children's fathers realised the importance of introducing their boys to male society without any feelings of shame.

Most of the cases showed how the father's role was perceived to be essential and how their absence creates a gap, sometimes limiting or influencing the child's potential to develop independence. The mothers also reported giving up physical training at other times either because of their health or failure to convince their children to accept the training. As explained by M12, the father was responsible for this, but in other examples when the mother was not able to train the child, she either hired a physical therapist at home, like M3, or skipped home training, like M2. From this, it can be understood that some mothers succeeded in filling the gap left by the fathers' lack of contribution either by being physically absent or not being supportive, and that sometimes the circumstances were not positive. However, in general the mothers did not elaborate on their discussions of the fathers' role, even though most of them were directly asked about it. This may point to the size or impact of the fathers' contributions to their children's development. Despite this, their presence was acknowledged most of the time, and the mothers mentioned their part in the children's training plans and decision making. However, the data showed that the mothers tried their best to minimize any gaps in the child training caused by the fathers' absence, whether this was due to the father's choice, or because the mother was protecting the child psychologically. The majority of the mothers

believed in the value of the father's contribution to the training process to be independent, if it was offered.

7.2.2 Beliefs about the role of siblings

For the majority of the mothers the presence of their disabled children's siblings was evident within the training process. According to the mothers' beliefs, the siblings helped, directly or indirectly, with the learning of a number of functional skills and the development of the children's independence. The children were encouraged to practice the skill so that they could join their siblings, and imitating their brothers and sisters eased the learning process.

M17 said that when her child was young, a physician recommended that she have another baby, as having an able-bodied sibling to interact with would help to develop the skills of her disabled child:

> *'I also blame myself for having his brother because the doctors told me if you have another child, s/he will help you a lot at home and share half of the responsibilities related to (child's name). That's why I had his brother. When I had (child's name), I wasn't thinking about having another child until (child's name) got stronger and became independent. I told myself: "Am I insane to have another child while the first one can't help himself?" I remember a Saudi doctor who told me that I was making the biggest mistake. He said, "if you want to help him, have another child for him. No matter how*

much you work on him, it won't help him develop like playing, fighting, and interacting with his brother; this alone helps treat and improve (child's name)'s condition", so I decided to have another child.

M17 talked about her hesitancy and guilt about having a new child that would require her care while her disabled child still needed her. At another point in the same interview she also mentioned that her disabled child was very attached to his brother and learned from him; she believed that he helped and encouraged him to learn many of the functional skills that helped him to develop independence.

M2 mentioned that her daughter played a part in teaching her disabled son many skills that helped him to be more independent:

'*He wants to go to the bathroom by himself. Even when he saw me teaching his sister to use the bathroom, he points to the toilet. He has learnt many things from imitating his little sister*'.

The mother mentioned that her able-bodied daughter's mastery of toileting encouraged her disabled child to learn toileting, and he learned other self-care skills from imitation. In another part of the interview the mother also said that she appreciated her older daughter helping to supervise him, put him to bed, and wash him. M2's child has four siblings, and he is the youngest. In the interview, M2 also mentioned that her son was very attached to his sisters and she recognised their contribution,

either as a support to carry some of the burden or as a model for her son to imitate, helping him to learn functional skills.

M1 used her other child to teach her disabled child skills and how to respond to her instructions, and found this to be an effective way to learn:

> *'He barely speaks. He uses simple words like "mama", "baba", etc., but thank God, he has improved a lot from before because his sister helped him speak; she chats with him. I always keep her with him and tell her to speak with him, and tell him this and that. We don't use sign language at all. His father and I talk with him to develop his speech'*.

Here, the mother acknowledges the sister's role in improving her child's speaking abilities by interacting with her son and emphasised the importance of developing speech. She also talked about discovering a teaching strategy involving his sister:

> *'Before, he couldn't learn anything, so I asked his sister to bring the remote control and she did, and he smiled. I feel that when he laughs, it means that he is getting what I said. Then, I asked him to bring me the remote control, to help him keep it in mind, and he laughs and brings it. He feels as if he has accomplished something, he can feel it. If God wills, he will improve … When he does something wrong, I sometimes talk*

to his sister, even if she didn't do anything, and she says: "Okay mom, I promise I won't do it again," so that he understands that it's wrong. He understands better when I try to teach him through his sister, and he doesn't know how to answer, so he gets what to say from his sister. He doesn't know how to reply usually, he laughs. When I teach him indirectly through his sister, he does understand and doesn't repeat the same mistake again. When he hears his sister's reply, he also says: "Okay mom, I won't do it again." This strategy helped a lot with (child's name) because he doesn't know much and can't reply'.

The mother focused on developing her child's cognitive abilities by guiding the sister in front of her son, giving her the instructions and letting him learn the response and copy it. The mother involved the sibling as a model and believed that watching the response helped her child in learning. She also described how her son learned from watching his sister undertake other functional skills.

Some mothers whose disabled children had older siblings discussed the support provided by them in taking on part of the child care responsibilities, which suggests that the siblings may have had a role in influencing the development of these children's independence. M3 said that the older sister (almost 15 years older) assumed part of the child-rearing responsibilities, when the mother was facing health problems.

She had undergone surgery for a brain tumour, which left her physically unfit and with unstable mental health, and needed her daughter to support her at this time, as she still had many child-rearing responsibilities. M3 mentioned that she took care of her disabled daughter and slept next to her. She also said:

> '*Although she is 10 years old, and there is an age gap, but (Subhan Allah) they are close to her. They don't leave her alone, no. And she imitates them, especially her older sister. I am nothing compared to her sister, nothing. She is her mother; like I told you at the beginning, this is her mother*.'

The mother recognised the strong relationship between her child and her siblings and that imitating them helped her disabled daughter. She even believed that their relationship was stronger than her own relationship with her disabled child. This supports the notion that siblings can make significant contributions to training disabled children to be independent.

The mothers realised that their children tended to imitate their siblings, and were encouraged when they trained along with them. Therefore, the siblings' presence, in the mothers' opinion, contributed to easing their children's learning of functional skills, which in turn helped them to develop independence. In some cases, the mothers used the support of siblings in supervising their children while practicing functional skills. From this, it can be understood that the mothers believed training a child

to develop independence to be a shared activity to which any member of the family can contribute.

7.3 Conclusion

In this chapter, the mothers' beliefs about training their children to be independent were examined. The mothers spoke about their training strategies, and elaborated on their practice regarding training. The data indicated that the mothers in some cases were motivated to train their children to be independent while in a few others they avoided training activities. The motivation was either to lessen their burden, especially the mothers of children with poor walking ability, to reduce the physical burden of carrying the child, or to allow the child to be able to separate from the mother. While one motivation was to obtain physical achievement, the mothers' avoidance was due to either physical or mental protection of the child.

The majority of the mothers talked about techniques they created to train their children to be independent. In most of these techniques, such as storytelling, repetition, encouraging, and comparing them with siblings, the mothers worked to the mental level of their children. From this it seems that the mothers believed that the mental abilities of the children, their confidence and self-belief, as well as the desire to improve should come from inside the child. These techniques, along with others like 'starting the task and having the child continue' show that the mothers believed in their children's role in the training process,

and provided information about their expectations regarding their contribution to the training.

The mothers also showed acknowledgment for the family member's – father or siblings – role in training their children to develop independent although the levels of support from them varied greatly. While expressing their beliefs regarding their children's potential and training, a number of key factors that influenced their beliefs and contributed in constructing these beliefs were identified. These will be examined in the next chapter, 'Factors that influenced belief development'.

8 Chapter 8. Findings: Factors that Influenced Belief Development

This chapter will explore the theme 'Factors that influenced belief development'. These factors take a middle stratum between maternal beliefs, as they are also informed by religious and cultural beliefs, and at the same time are very likely to have an impact on other maternal beliefs, as portrayed in Figure 8.1.

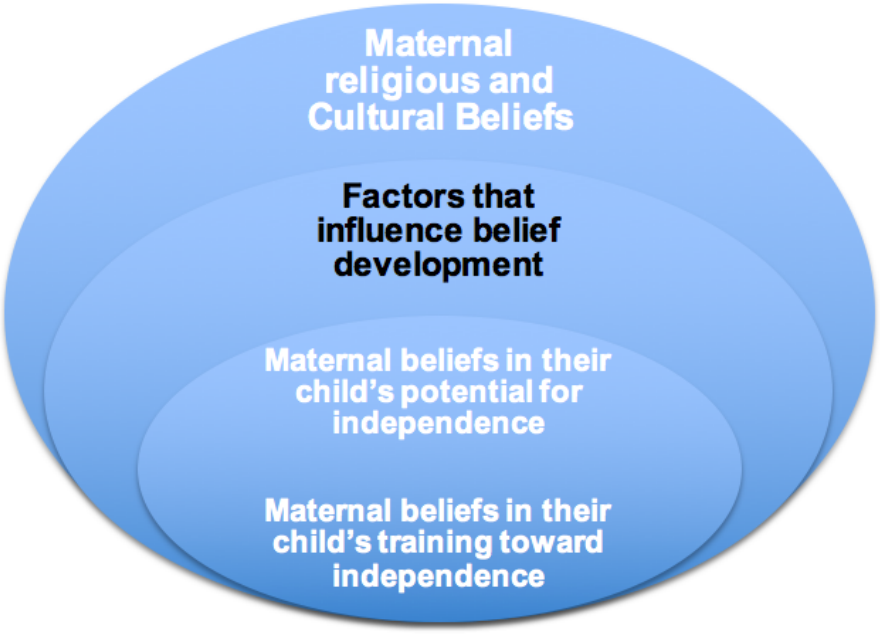


Figure 8.1. The theme 'factors that influenced belief development' and its relation to other themes.

This theme has three subthemes; the first looks at factors that '*related to the mother*': beliefs concerning the mothers' physical health and feelings, and maternal behaviours related to the child. The second

subtheme, aspects '*related to the child*' examines the mothers' beliefs regarding their children's potential and training, for example some of the children's characteristics, improvements, and health and speech status. The third subtheme, '*external factors*' explores the influences of society and extended family. Each of these themes was analysed and interpreted to show how they impacted the children's ability and performance, as well as the role they played in constructing the mothers' beliefs regarding their children's potential and training to be independent. This is illustrated in the following figure, 8.2.

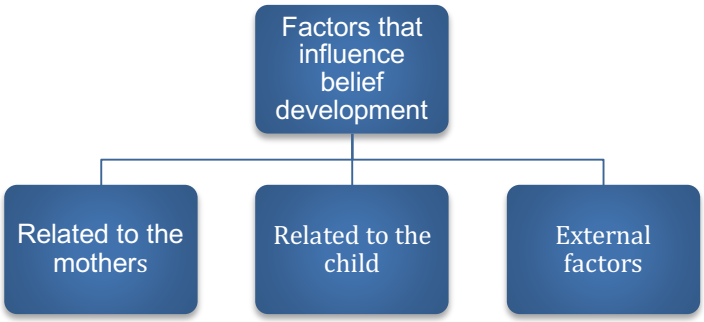


Figure 8.2. Subthemes of 'factors that influence belief development'.

8.1 Factors related to the mothers

In the interviews with the mothers it was found that they held some beliefs reflecting their feelings and physical health and their behaviours. These beliefs are also assumed to have a role as factors in influencing and constructing the mothers' beliefs regarding their children's potential and training. This section will demonstrate the ways in which the mothers' feelings, physical health and behaviours influenced their relationships with their children, their priorities and their training

processes, as shown in Figure 8.2. The possibility of influencing their children's performance and the relation between these beliefs will also be examined, and maternal beliefs regarding independence will be highlighted.

8.1.1 Mothers' feelings

This theme will address the mothers' feelings in the light of what they mentioned during the interviews about their feelings and thoughts concerning their children's status and future. The ways in which these beliefs may have influenced the mothers' beliefs about their children's potential and training to be independent will also be explored. These will include their negative feelings, beliefs about relieving their consciences towards their children, and beliefs regarding their children's future expectations.

Negative feelings

Most of the mothers voiced at least one negative feelin*g* because of their child's condition, for example blame, guilt, anger, depression, being dispirited. M8, for instance, mentioned that when her child was just born, he had a fever and she took him to the hospital. Later, the doctors told her that his mild cerebral palsy might have been caused by a virus contracted at the hospital when he was admitted. She said:

> '*I cried and wished that I had not admitted him to the hospital. I wished he did not have a fever. I wished I had not given him to that nurse [who] did these analyses and transferred germs to him because of poor hygiene, which caused this disability'*.

The mother regretted and blamed herself for something that had happened many years previously that she believed had caused her son's disability. She may also have felt guilty about this. M8 was also upset by the father ignoring her wishes and allowing their disabled son to sit in the front seat of the car rather than in the back like the other children:

> '*I am defeated by him and his dad. I want to talk. I want to shout at them and say that what they are doing is wrong. I want to raise him as I raised his siblings. They sit in the back seat, and he should be with them even if he cries or becomes intransigent'*.

The mother felt angry and frustrated that she was not respected by her child and that the father did not care about it. Her statement reflects her belief that her voice was not acknowledged, that she was not raising her child like his siblings, and at the same time that it was out of her control. The mother's articulation and her emotions while talking gave the impression that she was frustrated about her role in her child's training process, which may have influenced the efficiency of her guiding her son's behaviour and enhancing his ability to be independent.

Relieving self-blame

Some of the mothers mentioned relief from self-blame toward their children as one of their motives during their children's training. For instance, M2 shouldered all of the responsibility for her son, with moderate cerebral palsy, who had not mastered his self-care skills and used a wheelchair:

> '*I do my best and do everything I can do, so that he doesn't blame me later or feel that I haven't given him all his rights'.*

By training her child or seeking treatment the mother hoped to avoid self-blame and the possibility that she might be blamed in the future by her child if she did not make sufficient effort. This way of thinking reveals that part of the mother's effort in training her child might have been be motivated by the belief that this was part of her job as a mother, therefore avoiding feelings of guilt. This suggests that a child's training process might be influenced not only by the child's status, but also by the mother's beliefs about what she is required to do and her duty as a mother.

Future expectations

Many of the mothers elaborated on their future expectations. Most expressed optimism when they talked about their children's future;

however they tended to talk more about general improvement and rarely gave specific descriptions of their conceptualisation. M1 was optimistic about her son's future, and was focusing on his training, to which he was responding and improving. M1 described the moment when she first discovered his mild cerebral palsy and what she thought about his future:

> '*I was shocked at first! The doctor told me he was not going to grow up like normal kids, but I considered improving his condition, if God willed, he would be like normal people with time. I also thought that his father and I would work together on teaching our son, and if God willed, he would improve'*.

Despite what she had been told by the doctor, M1 said '*I considered improving his condition*'. This reflected her belief that she had a role to play in improving her child's condition and that it was her decision. She described her conceptualisation of her son's improvement to be like '*normal people*', but mentioned more than once that his improvement was linked with God's will, giving value to the power of God for her son's improvement, and clarifying how her religious beliefs informed her convictions about him. At the same time, however, she also emphasised her own work in improving her child, reflecting her realisation that his improvement was linked with her belief in her ability to work on, and succeed in, developing him.

Some mothers had pessimistic perceptions of their children's future; M2's child with moderate cerebral palsy, moved using a wheelchair, and most of his training happened in a rehabilitation centre. The mother carried out all of his self-care skills and did little in the way of training. Asked what she thought about her child's skills in the future, she said:

> *'I don't feel, I mean not about feeling, I know my son will not be able to hold a spoon, that's it! I know so I don't put in my mind that he will one day hold the spoon because his hand is weak, you know? I don't give myself big hopes that he will hold a spoon'.*

The mother was certain about her child's future eating ability, being pessimistic about developing this skill due to his muscle weakness. This attitude might have influenced her efforts during his training towards independence, as evidenced by the fact that she did not mention any plans to improve his muscle weakness.

Some of the mothers expressed the reasons why they had fears about their children's future, which may have influenced how they thought about their surrounding circumstances. For example, M8's child with mild cerebral palsy improved and responded well to training. M8 was like M1; they both believed that improving the child was the mother's decision. But M8 also mentioned that her fear was due to her presence not being guaranteed in the future, and thinking of the poor services that existed for disabled adults:

Researcher: *‘You said nobody will sit with him, can you tell me more about what you think on this point?’*

Mother: *‘I mean, this world is life and death and I won’t be with him for good; even his father, I mean, I’m thinking when he gets older who will take him? We don’t have a centre to take care of these cases and supervise them and you can not guarantee relatives. There are no centres that at least make monthly checks or help to teach skills to work and become economically independent. I don’t think we have this in Saudi’.*

In this quotation, the mother expresses her fears about her child’s future, complaining that she cannot guarantee relatives’ support, and there is no governmental support for disabled children. Although during the interview the mother seemed to appreciate her son’s improvement, her words reflected her beliefs about his level of independence, feeling that it would not be sufficient and he would continue to need at least supervision and guidance.

On the other hand, some mothers said they avoided thinking about the future. M17’s child with mild cerebral palsy responded to the mother and slowly improved:

‘*This is what matters most to me. I want him to carry himself. I haven't thought about the things he should do independently, but I don't want him to need anybody in general when I am not there. Sometimes, I feel it's*

difficult to achieve this, and sometimes, I don't want to think about it'.

M17's target for her child to 'carry himself' was an expression of her wish for his future independence. She was not thinking of details, but her main concern was that he would not need assistance from other people when she was absent. She also acknowledged that this would be difficult to achieve. It might be that the mother's sporadic avoidance of thinking about the future indicates that she was evading pessimism, but at the same time she was not seeing signs of improvement. The mother's avoidance of putting a particular conceptualisation on her son's future independence might also reflect that she had no well-defined goal in mind when training her child to develop independence.

While M11 and M14 mentioned that they focused on the present moment and could not anticipate their children's future, they might have believed that thinking of the future would influence their training and distract them from their focus. At the same time, it should be recalled that M10 believed in the possibility of being surprised by her child's abilities, as was seen in Chapter 6.

Most mothers tended to show optimism about their children depending on their progression, or because of a notable Islamic teaching, 'trust in Allah', which means to think positively about what God will award. The majority of them did not conceptualize their

children's improvement. Thinking of the future in most cases motivated the mothers to think about preparing their children for separation and social abilities.

Focusing on the mothers' feelings and interpreting their articulations while they were linking their feelings with their practice or thoughts regarding their children provided explanations as to how these feelings might have impacted on their beliefs about their children's potential or training to be independent.

8.1.2 Mothers' physical health

The physical health and abilities of the mothers hindered them on some occasions from contributing to training that required certain physical activity. Some of the mothers had physical limitations from pregnancy, or health problems that made them reluctant to participate in training activities, or caused them to avoid them altogether.

M3's health problems, for example, had necessitated multiple brain surgeries, and she mentioned that her health had prevented her from training her daughter:

> '*Do I make an effort to do her therapy? No I can't; I have my medical problems. I can't at all, I feel tired if I hold her for little bit; I can not at all, I mean, I will sit or fall down, me and her. Basically I can not stand for a long time'.*

The mother clarified that her physical limitations prevented her from holding her child or standing for long periods, and therefore she was unable to train her child. She explicitly described her physical limitations preventing her from making a full contribution to her daughter's training to develop skills that enhance independence, especially those that required physical efforts such as walking or toilet training. This reveals part of the mother's beliefs regarding her child's training; it reflects her priorities, showing how she linked her health status with her practice while training her child. Furthermore, some of the mothers, for example M1 and M7, mentioned that they were unable to train their children when they were pregnant.

There was also a focus on the mothers' physical ability. M13's child with moderate cerebral palsy had not mastered any functional skills. The mother mentioned that she carried her daughter while she was crawling, and when asked why, she said: '*I can put her in the walker, but I find it unnecessary to make her stand up as long as I can carry her'*. The mother focussed on her own physical ability when deciding whether to support her child or let her practice the task, and not a belief in the importance of giving the child the chance to practice and develop her walking.

The mother's health could have acted as either a motivator or a discouraging factor that influenced the mothers' beliefs regarding training their children to be independent. But it also might have led the mothers to support their children while practicing activities, which might have set back the children's progress in mastering skills. M13

highlighted her physical health as a factor in the planning of her daughter's training routine, suggesting that this influenced her beliefs regarding her priorities and the contribution she made to her child's training. At the same time, she planned to compensate by passing the responsibility to someone else (the father or physical therapist). This also reflects her beliefs about the importance of her role in training her child and awareness that her health limitations may have caused a gap in her child's training.

8.1.3 Mothers' behaviour

In the interviews the mothers talked about some of the behaviours that they practised during their children's training or the daily routine. These included physical and psychological protection, the mothers' childrearing – varying from firmness to flexibility and pity – and the mothers' patience and effort during training. The beliefs behind these behaviours were found to influence the children's performance and training towards independence. This will be explored and interpreted in this theme using codes representing the main behaviours captured from the data.

Protection

The mothers' protection of their children was manifested throughout the interviews in different behaviours. The mothers were trying to protect their children from physical harm, for example falling, or psychological harm in social interactions.

Physical protection happened in most cases when the mothers hesitated about separation and wanted their children to be under their supervision. The mothers justified this through their fears of the child falling or experiencing physical harm. For instance, M12's child with mild cerebral palsy used a walker and had mastered almost all of his self-care skills. But M12 still hesitated to allow him away from supervision:

> Mother: *'He asked to go to (cousin's name). He kept asking me to go to him, he wants to play with him, he goes with him and his friends come sometimes, stay and play on the PlayStation with them, the boy is not dependent, ok, we tell him to go but I am of the kind who's afraid honestly'.*
>
> Researcher: *'Talk to me about this point'.*
>
> Mother: *'I'm afraid he'll fall down, afraid that someone will hit him'.*
>
> Researcher: *'Talk to me in detail about this area, I want to know more'.*
>
> Mother: *'People said he might be better if you leave him a little, he sometimes said let me sleep over in my auntie's house for example, "mom I want to sleep in my auntie's house, is it ok?" I refuse – [he is]silent – I don't know why I don't like him to go'.*

Although M12 generally wanted to develop her son's social abilities, her fears of him falling or being hit during social interactions made her want to keep him under her supervision. This was interpreted as physical protection of the child, and it appeared to overcome the mother's desire for developing his social abilities. In this example, physical protection influenced – albeit not directly – the physical improvement of the child. It also reduced his chances of separation and in turn, therefore, his potential to achieve independence.

Many mothers talked about what can be understood as physical protection when they described and justified their supervision of their children's social interactions with other children. For example, M16's 6-year-old daughter had a head shunt that was delicate, and if she fell down, it could have required surgery to fix it. She had fallen and had surgery several times previously, so her mother was worried about it and would supervise her while she was playing with other children:

> *'I was afraid she would fall and get hurt, maybe because she is sick and had many surgeries from falling down and changing the shunt that makes me feel it is impossible that she can be independent. A point I want to say, I cannot leave her alone with the children, she needs intensive supervision; she fell six times over the shunt and every time [she had] surgery and the doctor warned me that this is not good for her. That's why I never leave her with the children alone. The children in the family are very active and she does not have balance; she might fall down by herself without any one pushing her. What about if she plays with*

them? They will push her and she will fall … I don't prevent her from playing with them but I just supervise her from a distance or sometimes I hold her if they play race and I feel she is very upset but this is for her benefit'.

The child's medical background caused the mother to believe that her daughter needed intensive supervision, and she provided physical protection to prevent her from falling and the complications that might arise from it. She realised at the same time, however, that this might limit her daughter's social activities. When she said '*I feel she is very upset but this is for her benefit'*, the mother can be seen to be prioritising physical protection over psychological protection. The mother's fear, interpreted as physical protection, limited the child's development of functional and social abilities and therefore development of independence. In all of the previous examples, the children had mild cerebral palsy and were at the stage of preparing for separation; however, they all had poor balance, which made their mothers reluctant to leave them unsupervised. This may have influenced the number of activities they participated in and their social abilities. It also may have affected their self-confidence and ability to initiate and independently undertake physical tasks, which is part of developing independence.

The mothers' beliefs about the importance of psychologically protecting their children offers further understanding of their beliefs regarding independence and how they prioritised what they perceived as the children's safety over development. M6, for example, focussed on her child's personality, telling all of her family members to be careful when

talking about her child in his presence and to teach their children the same. She said, '*I want to set limits for people*', demonstrating that she wanted to control the surrounding people's behaviour towards her child to protect him psychologically. M12 was careful not to focus on her child's mistakes when undertaking speech training so that he did not become disheartened. M10 mentioned that sometimes she saw it as advantageous for disabled children to have a low level of understanding because they could not interpret people's references to their disability. M10 placed a stronger emphasis on her child's feelings than her desire to develop her son's understanding, although on another occasion, she appeared to realize that understanding would help him to be independent.

Another form of psychological protection that was found in some cases was the mothers' compassion towards their children. For example, M2's seven-year-old son, with moderate cerebral palsy, moved using a wheelchair or by crawling. His mother said that when she saw him crawling and trying to follow his siblings in play, she felt compassion towards him and sometimes carried him to allow him to follow the other children. The physical intervention from the mother was motivated by her emotions towards her child. This suggests that in some respects, the mothers' beliefs may lead them to prioritise their emotional feelings towards their children, or their desire to protect their children, over their functional development, and this, in turn, is reflected in their progression towards independence.

Mothers' childrearing strategy

This theme will examine some behaviours of the mothers related to childrearing that were mentioned during discourse about the children's training or daily routine. It will capture the occasions when the mothers became firm or flexible, or tried to rely on others in relation to training, and how these factors may have affected the children's performance, and therefore, their functional development.

Some mothers were firm during the training process. For example, M10's son, with mild cerebral palsy, had mastered most of his self-care skills. M10 insisted on training him in toileting even though the doctor had told her that it was almost impossible. She believed he had learned toilet training because she was firm in her training:

> *'I feel he understands: when he is hungry he asks for food; he said "this is picture this is paint, this is red this is green", how can't he be trained for the toilet?! I wasn't convinced; I worked on him while he was four, I was taking him to the toilet, ok? […] He was punished in toilet training. I was hitting him every time he did it on himself, and punished ok? From four years until six years. I can say now, we can say, we have finished this stage; you will ask if I used firmness? Yes I did use firmness'.*

The mother was clear that she was firm in her toilet training, punishing and hitting her son. It is also worth mentioning that parents hitting their

children is not considered child harm or abuse according to the 'child protection system' in Saudi Arabia; therefore, the mother's statement that she hit her son did not necessitate informing the officials in the rehabilitation centre.

On the other hand, only a few of the mothers showed reliance on external support to control their children's behaviour or to convince them to learn skills. For example, M2's son only practised walking training in the rehabilitation centre, while crawling or using the wheelchair at home. His mother said that he refused to walk with her, which made her depend on the physiotherapist in the centre for the training:

> *Mother: 'He doesn't walk at home but walks here with the teacher. My son needs someone strict now. Here when the teacher asks him for walk training he stands up and does it with her, he is afraid of them but not of me. I tried to do it at home but he refuses to walk with me. Researcher: 'What do you find is the solution in this case?'*
>
> *Mother: 'The solution is to bring him and let them force him to walk, I give him people who are stronger than me, because me he might break my heart and I say poor [boy] he got tired, and let him sit, here "no walk" means "walk"; anyway, he will walk, then he will get afraid and walk with her, here they know for him, they know how to make him straight. At home he gets spoiled, here no'.*

The mother showed flexibility with her son, realising that he needed firmness to be trained for walking, but that it could not come from her. She appeared to have given up, regarding her laxity in training her son, and described this as her compassion towards him from tiring him. M2 did not show a strong focus on walking training, believing it to be part of the therapist's job. This behaviour might reflect her beliefs regarding her role in training her child to be independent.

The mothers' childrearing was not directly related to developing the children's independence, but the mothers' beliefs about the level of firmness or flexibility they employed while controlling their children's behaviour during training, and their beliefs about reliance on others, such as teachers and therapists, can provide information on how they value their role in training their children to be independent.

8.1.3.1 Mothers' efforts in training

In the interviews, it was found that the mothers realised that the amount of effort they put into their children's training impacted the children's development. Some mothers stated that to expect results, 'hard work' was required during the training process. For example, M10 focused on her son's training, and he had developed most functional skills:

> *'Look, I will give you the summary: Whoever has a child with special needs must work hard. If she can't work hard, she must bring people in who can work hard. If she just has one disabled child, she dedicates herself to that child and works hard. Don't*

say the child will not learn toileting or how to read or that the child doesn't understand'.

In this extract, the mother's belief in working hard relates to the mother herself or to other professional people. She refuses to lose hope in terms of child development and feels committed to training her son, reflecting a belief not to judge according to the child's status and to be committed to work hard to obtain results.

Examining this belief, 'importance of providing effort in training the child', clarified how some of the mothers believed independence could be achieved, describing the quality of the training process by expressing their beliefs about the importance of making an effort during training. This provides information about the mothers' beliefs concerning their contribution to the children's training.

8.1.3.2 Mothers' patience in training

One of the features highlighted by the mothers was to be patient during training and not to expect rapid results. Some said they realised that the training of their child required them to be patient and expect a lengthy process to achieve results. As well as hard work, M10 mentioned being patient as the other way to achieve positive results:

'*Number two, being patient, patient, patient; the road is long, long, long. Mothers should remember when they feel sad or*

cry about their child that the child will not change quickly, and God's will, will happen'.

In this extract, the mother emphasises the importance of being patient; she understands that the mothers of disabled children will face negative emotions and low energy, and that patience is necessary as improvements can take time, at the same time highlighting her belief in God's will. It is worth noting that it is within Islamic teaching to be patient towards life's difficulties, and believe in God's omnipotence to change them and give rewards.

M13 also emphasised being patient; her child was born with severe cerebral palsy, and when she focused on her daughter's training, she improved to moderate cerebral palsy:

'*Be patient and penitent. Just imagine, dealing with a six- or seven-year-old child with the ability of a one-year-old child, although she discriminates while not talking*'.

The mother emphasized the importance of being patient to be able to bear the burden of training her child with poor abilities. Both mothers believed that being patient would support them during the training process to accept their slow development towards independence.

This theme looked at some of the mothers' beliefs that were related to the mothers' feelings and physical health in areas related to their children's status and future, and some behaviours that were motivated by their beliefs, which might have had an impact on their children's performance or abilities.

8.2 Factors related to the children

The mothers also discussed their convictions regarding their children that may have influenced their beliefs regarding their children's potential and training to be independent. In this theme, these beliefs will be examined, capturing the children's characteristics such as wishes or negative behaviours, as well as the mothers' beliefs about their children's improvements in developing hope and motivation and the impact of this on the mothers' feelings. Furthermore, the mothers' convictions about their children's health and speech status will be analysed and interpreted and linked to the children's performance and development of abilities, therefore providing more understanding of the mothers' beliefs regarding the development of their children's independence.

8.2.1 Children's characteristics

Child desire

In the interviews, the mothers described some of their children's characteristics that they believed influenced their performance or the development of their abilities. The main characteristic that many of the mothers mentioned in different forms was their children's desire as motivation to develop. Desire to carry out a task means either that the child realises that mastering this task will develop their independence or not. Many of the mothers believed that when their children really wanted to develop a skill, there was a greater chance for it to improve and that

their children were mainly motivated by their desire to improve. For instance, M6's seven-year-old son with mild cerebral palsy was developing most of his functional skills. The mother focussed on her child's training:

> Researcher: *'You just told me that you believe he will get rid of the walker one day; talk about this more'.*
>
> Mother: *'Yes, because he responds, [child's name] responds, loves encouragement he loves depending on himself, he wants to depend on himself. For that I feel he will, I mean, thank God, he has a good future".*

The mother was optimistic about her son's improvement having considered his feedback, stating that he 'loves' and 'wants' independence. M6 had a positive attitude, relying on her belief in the effectiveness of the child's desire in motivating him to train and therefore develop his functional skills. This shows how the mother focussed on the child's beliefs and convictions and linked them to his contribution to his own training process.

M2's seven-year-old son with moderate cerebral palsy had not mastered most of the functional skills for his expected stage of development, and moved using a wheelchair. M2 believed that he imitated his sister because he loved her, because people who love someone will copy them; his desire to imitate her motivated him to do the task:

> ‘*I saw him loving her, asking for her. You know, when children love someone, they will act like them, right or not? Even old people, if you love someone, you try to own that person by your action or talk. He loves her, and he is the kind of person that if he loves, he will imitate immediately’*.

Here the mother realises the impact of the child’s desire to be like his sister as a motivation in the training process.

M17’s seven-year-old son with mild cerebral palsy had not fully mastered all functional skills. The mother focussed on training her child, mentioning that she felt that he did not have the desire to develop eating or dressing skills:

> Mother: *‘His hands are weak, and he still doesn't want to put on his clothes by himself. He is preoccupied with other things; he wants to play. I feel that if he has a strong incentive, he will be capable of doing things. If his father is in the car and is going to take him somewhere that he loves, you will be amazed at how fast he does things. He does things quickly – not quite normally – but what he does usually in two hours is minimized to half an hour; of course, with my help, not alone. I regard this as an improvement, to say the least’.*
>
> Researcher: *‘Why do you think he does these things slowly when there isn't anything that motivates him?’*

> Mother: *‘He doesn’t feel it's important. He doesn't feel that he should change his school clothes and wears pyjamas when he comes back home. He is not convinced at all. What matters to him is that he plays, comes back home, sees his brother and eats. He refuses anything that requires an effort; for example, until now, he refused to eat with a spoon’.*

The mother attributed her son’s delay in mastering dressing skills and his low performance to his desire not to learn, believing that even at his current stage of development when he is motivated, he can dress in a shorter time with assistance. The mother conceded that her son’s belief about the importance of learning could have influenced his ability to learn and master functional skills. This shows that the mother believes that part of the responsibility for the child training process belongs to the child.

The mothers in these examples believed in their children’s efficacy in contributing to their own training process and also that the children’s beliefs and wishes can be a motivation to develop tasks. This belief also provides information about how the mothers understand their children’s role in their own development to achieve independence.

Child negative behaviours

Some mothers mentioned, in different forms, their *children's negative behaviours*. They believed that these behaviours could have had an impact on their children's performance and caused difficulties during the training process, such as being intransigent. This reveals some factors that might have had an influence on the mothers' beliefs regarding their children's training.

For example, M3's daughter is nine years old, has moderate cerebral palsy and had not mastered all functional skills. M3 believed that her child could control her urine and evacuation, yet she was not able to toilet train her. She felt that her daughter needed to help her with toilet training as long as she understood, and she also linked the delay in toilet training to what she perceived as intransigence:

> Mother: *'Is she punishing me, punishing me!!? Is she punishing me with this!? I take her to the bathroom and she spends half an hour there, and my back hurts, then I drag her to the room, and sometimes she gets intransigent and does it on the floor, just because I simply carried her and took her, I don't know. I feel that she is punishing me with this behaviour*'.

The mother believed that her daughter was not cooperating with her in toilet training on purpose, because of her intransigence and to make her angry, and she believed that her intention was to tire her out in training

without learning. It is worth noting here that the mother mentioned on another occasion that she was absent during her child's early stages because of her health problems, and she believed that her child was punishing her because of this. This mother, as seen in Section [6.2.1.3], also mentioned that her daughter's poor balance had also caused difficulties in toilet training.

Shyness was another negative behaviour of the children that some mothers believed influenced their children's performance. For example, M19's 10-year-old son with moderate cerebral palsy was able to walk using a walker yet refused to. M19 believes that this was because he was shy: '*you know I take him to the beach and mall for refreshments and there are long walks but he refuses to use the walker in front of people; he is shy*'. The mother recognized that her child's shyness prevented him from practicing using the walker in public, and she mentioned that she did not push him to walk outdoors. The mother's decision not to push her son shows that she appreciated his shyness and prioritized his feelings over his physical development.

The data revealed that according to the mothers' beliefs, some of the children's own characteristics might have impacted their development. The mothers believed that these characteristics, if positive such as the desire to improve, may have helped to improve the children's performance and accelerate their progression towards independence, and if negative, such as intransigence, may have contributed to delays in the mastery of skills and development of independence. These beliefs provide information about the children's roles in their own

training, and the efficacy of these roles in developing their own independence.

8.2.2 The impact of children's improvement

In their explanation of their children' progression the mothers talked about how their children's improvement impacted the training process, providing hope and motivation for further training, and positively influencing the mothers' feelings.

Most mothers talked about their hope after noticing some improvement. For instance, M6 had focused on her son's training, and he had developed most functional skills:

> '*Hope in God is big. I mean, thank God. He made him walk. I was thinking he wouldn't walk then he walked; that he wouldn't talk, then he talked. A lot of things come to my mind, you understand me? He was not able to learn colours and numbers, and it was far from my mind that he would learn. But, thank God, he did. I believe he will get better*'.

The mother started this statement by saying '*hope in God is big*' to show immediately that any hope for her is due to God, and she goes on to mention her gratitude to God that her son was able to walk. This reflects the depth of her religious belief, and also the role of religion in guiding the other mother's beliefs. The mother mentioned her son's

improvement in skills when she wasn't expecting it, and although she attributed this to God, it provided her with more hope in her son's future improvement, which might in turn have influenced her beliefs in regard to his chances of achieving independence.

Some mothers mentioned that their children's improvement motivated them to train them and also influenced their own psychology. M5's eight-year-old son with moderate cerebral palsy, for example, had had severe cerebral palsy in his early years and was not responding to training. M5 said:

> Mother: *'He changed 180 degrees; when he started to talk and understand I went to hospitals. I wanted to treat him because I saw communication. Before there was no communication, even if I talked, [he was] like a wall, no results. When he started to respond I knew I had to push him and teach him.*
>
> Researcher: *'Talk to me: what about before?'*
>
> Mother: *'As I told you there were no results; he was not responding with me. I don't know what his case is; is it his ability? Or like other children I used to see in hospitals where the mothers look dispirited and the children floppy and hanging their heads. I used to have dispirited occasions according to his case; the mother's feedback depends on the child's case. For example, in one of the stages he was indolent. I don't know what was the matter with him, he*

influenced me negatively that's it. I took him one time to therapy and the other, no. I felt that I was a mother not like those strong mothers, then after a while, when he started to develop I took him to this school and to the doctor; the doctor told me "don't bring him any more" and he started to speak and improve. I started to take him to physiotherapy and occupational therapy and then he started to know. I mean, this gave me a positive push; every time he is positive he gave me a positive push'.

When her child was not responding she felt dispirited, but this changed completely when he started to respond to her training and improved. This also motivated her to seek more training for him. She did not start training her child until he showed a response and improvement, and she said that his improvements motivated her each time to give further training. This indicates that some mothers might need to draw confidence from their children's improvement to commence or continue training to develop independence. The children's rate of progression may therefore impact the mothers' feelings and behaviour towards the training process. Understanding the ways in which the mothers' beliefs were linked with their children's progression may provide information that helps in understanding the mothers' beliefs regarding their children's training and chances to achieve independence.

8.2.3 Children's health status

The findings also revealed that few mothers believed that their children's health and growth might have had an influence on their children's abilities.

Health complications

In some cases, they attributed their children's delays in skills mastery to their health problems. It should be noted that the health problems referred to here do not include developmental delays, such as poor balance or muscle weakness, but include complications that happen as a result of the disability, such as pain, muscle shortening, or seizure. For instance, M19's son, with moderate cerebral palsy, had mastered some self-care skills and had difficulty in walking:

> '*He suffers from pain in the muscles, look – let me tell you there is some tightness in the tendon from the back; you can see the muscle is a little tight. He can not extend his leg straight; I mean there is pain, let me tell you when they make him exercise and walk with the walker he feels the pain … I don't want to put pressure on him, I know that basically there is pain in the legs, which makes him tighten in an abnormal way, and when he sits he doesn't want to stand*'.

The mother recognises her child's muscle tightness and pain, and believes it to have caused difficulties during his training, limited his opportunities to practice walking, and therefore may have affected his abilities. Her belief may contribute in shaping her convictions regarding the training process of her child, as his condition may also influence the amount of pressure she applied during the training process.

Seizures were one of the health conditions a number of the mothers mentioned that they believed hindered their children's development. M8, M5, M12 and M18 mentioned that the seizures caused them to delay their separation from their children and keep them under supervision. M5's son had seizures when he was younger:

> '*I woke up and found him in severe seizure status, his eyes were up; we took him to the nearby health centre and they didn't know how to deal with him, then we took him to the hospital; they treated him and asked me how long he had been in seizure, I said maybe more than half an hour, I don't know, maybe one hour or one hour and a half. Can you imagine all this time in the car, then after that I concluded that he has a disability from the seizure that lasted such a long time … then because of the seizure he has a delay in sitting down, and he started to crawl then I started to know*'.

The mother believed that her son's seizures had made his condition deteriorate and in turn this had delayed his development. Seizures are

typically not predictable, which may cause more anxiety for the mother. Moreover, if she believed that this exacerbated delays in his abilities, she might have felt that external factors could continue to influence his development.

The mothers who mentioned their children's health complications believed that their health problems interfered with their children's development concerning some skills related to the problems. These mothers, in most cases, appeared to avoid pressuring their children while training, and in some cases, they did not mention their plans for solving the problem. This indicates that these mothers may have believed in external factors, which were beyond their control, hindering their children's training. This in turn may have influenced the mothers' beliefs about their children's chances of achieving independence and might have led to some discouragement or minimising of the focus while training a related skill.

Child growing up

Talking about their children's development, some mothers mentioned that they 'will' or 'might' master skills and develop independence while growing up. Therefore, they were keen, to some extent, on the idea that the older they got, the greater their opportunities would be to master the skill.

M16's six-year-old daughter with mild cerebral palsy had mastered some self-care skills. M16 said:

> ‘*There are things now I believe she cannot do, or doesn’t know how to do these things. I tried with her once, twice, and three times and if I see that she can’t, like riding the car, I wait for a while and see that she can’t, [because] the car is little high; I tried and feel she can’t, but maybe when she gets older she might, or not sure she will be able … even in her dressing, some clothes are small […] she tries to wear them but she can’t. When she grows up, gets older, sure she will be able to wear them because she is old enough*’.

The mother thought that her child’s limited ability in mobility or self-care skills was due to her age, and believed that as her daughter got older she would find it easier to master the skills and therefore achieve independence. It is interesting that the mother did not mention her daughter’s disability as a reason for her delays, which might also reflect the mother’s belief in the possibility that her child would improve as she got older.

Believing that children’s functional skills develop as they grow up was a regular assumption for able-bodied children. The mother’s convictions about the connections between her daughter’s disability and her age might stem from observations of her child’s previous improvement. It also points to the mothers’ beliefs that external factors beyond their control can assist in improving their children, so that they may allow

more time to master their skills. This may also affect the mothers' beliefs about training.

Some mothers were optimistic and considered that their children would improve with age, in a similar way to able-bodied children's development of independence. These mothers thought that growth was a factor that contributed to developing independence, and considered it when evaluating their children's level of independence and while training them.

8.2.4 Children's speech status

On many occasions, the mothers talked about their beliefs concerning the role of speech in enhancing their children's independence, and some categorised it as a way of evaluating and developing child independence. For example, both M5 and M12's children could speak, and the mothers wanted to improve their children's social abilities. They felt that developments in their speech would enhance their children's interaction with their peers, but that this might not directly affect their independence. On the other hand, however, M6's child had a hearing problem when he was young, and his mother thought that this had affected his speech. She believed that progress with his speech would allow him to communicate with people independently, which in turn would encourage her to separate from him and allow for more independence. To accommodate this, she added speech therapy to the training plan.

M2 and M13's children could not speak clearly, and the mothers wished that their children were able to express themselves. M2 said:

> Researcher: *'You talked to me before about speech. Tell me, what is the importance of speech in your opinion?'*
>
> Mother: *'Speech may be expression to me; tomorrow, for example, I won't understand him if he has pain – he might cry, but he will not express the thing that caused the pain, not like speech. It's important for everything; he can tell me what is painful, and when he gets older the little boy will be a man. I want to understand about him, I want him to express about what he feels deeply; now he is a child, I don't feel tomorrow he will be a teenager, he will be a man he needs to vent, every one needs to vent: right or not? Speech is the most important thing for me, tomorrow he will need to complain, if he did or needed something I can understand him this way. At least if he speaks he can read the Qur'an'.*
>
> Researcher: *'How do you link speech with independence?'*
>
> Mother: *'In everything. If he becomes independent … he needs to voice his opinion and impose his opinion; now you can see a child, in one or two years when he speaks he'll impose his opinion, right or not? When he speaks he becomes easily personally independent, imposes his opinion and tells you "I want this thing" but when he speaks poorly he cannot impose his opinion or express himself*'.

The mother believed that speech was important for her son to be able to express himself, especially with her, and to be able to tell her his thoughts, feelings and needs. She also linked speech with his ability to read the Qur'an. In Islamic teaching, reading the holy book is required for every Muslim, although reading does not require speech. However, the mother might have wanted to hear her son reading it out loud, which reflects how her religious beliefs might inform her beliefs about him. The mother articulated her belief that speech encourages independence of personality by allowing her child to express, and as she put it, '*impose'* his opinion. This may also indicate that the mother thought her son would be able to defend his opinion, which would make him less dependent on others to manage his communications.

It was also found that speech was mostly linked with independence of personality and a child's ability to communicate; however, some of the mothers mentioned speech while ranking their priorities in developing independence. For example, When M8 was asked about her independence priorities, she said '*Understanding, then walking, then speech and then self-care*'. M15 also said that she prioritized '*walking, then speech*'. This indicates that the mothers valued communication through speech and linked it with independence, which provides information on how the mothers understood their children's independence.

For some of the mothers, speech was considered a factor that supported their children's ability to communicate independently and to express their thoughts, feelings and complaints, which in turn was believed to contribute to developing their independence of personality.

8.3 External factors

During the interviews, some mothers talked about circumstances that they believed may have affected their children's development by influencing their performance or their chances of improving their abilities. They were referred to as 'external factors' because they came from the mothers' and children's surroundings, including the extended family and various societal influences. By interpreting the data, it was found that the mothers' convictions regarding the impact of these factors may have contributed to the construction of their beliefs regarding their children's independence. This theme, 'external factors', will be examined by splitting it into two subthemes, 'extended family', and 'surrounding society' in the following section.

8.3.1 Extended family

The extended family in this context includes the mother's and the father's families and the close relatives who meet the child regularly and with whom the child interacts. Most of the mothers in the sample mentioned their extended family, in terms of their relationship with it and its impact on their children.

For instance, M9's son, with mild cerebral palsy, had developed most of his functional skills. M9 focussed on her child's training, but believed that her family was lenient with him:

> *'My family have strong fears about (child's name), before when he had just started to walk I was putting a helmet on his head, ok? And they were very, very, what can I say, following him everywhere, and kept telling everyone to watch him, not to [let him] fall, but I was telling them "it is ok if he falls he will learn; next time he will not fall"'.*

M9 recognised that her family members were protective and intervened with her training plans, and therefore decided to minimise visits to her family so as to be able to control the training of her child within her rules. She noticed the influence and took action to avoid any impact on her son's training.

M8's child, with mild cerebral palsy, was in the process of developing self-care skills and had mastered most of them. M8 realised that her family were very flexible with her child, giving the example that they did not ask him to clean up after he finished eating snacks, which made her limit her visits to them. M8 was trying to avoid her son growing up with a sense of special treatment and not having to abide by the rules because of his disability, because she believed that it may have had an impact on his self-care skills development. Moreover, her son may have developed a feeling of being different from other children, which would not help in

developing independence. The mother also believed in the possibility of external influences affecting her son's performance or development of abilities – in this case her family's intervention – and decided to prioritize her child's development over family visits.

On the other hand, many mothers talked about their family's support, from moral to physical and financial aid, particularly in helping them take care of their children. For example, although M10 had focussed on her son's training, the father had withdrawn from the whole care and training process. M10 said that her family was very supportive. She mentioned that they provided her with a car and driver because she had transportation problems when taking him to hospital appointments, training sessions and school, and they also took care of him while she was away. This support gave her son a chance to be trained and supervised by professionals and allowed separation from the mother, which generated more independence for him. Therefore, she believed that her family's support impacted the child's training. M2's child, with moderate cerebral palsy had not mastered any self-care skills. She mentioned that her family was not supportive and refused to supervise her child even when her little daughter was admitted to the hospital. The poor support from the extended family might have affected the mother's motivation to train her child, especially if her child was highly reliant on her, and might have greatly reduced her opportunities to practice separation.

In Saudi society, the extended family is expected to be involved in the grandchildren's lives; the majority of the mothers knew this and tended

to limit contact if they believed it negatively influenced their children. At the same time, the mothers believed in their family's role, and appreciated their support during the training of their children, where it was offered.

8.3.2 Surrounding society

This theme will explore the mothers' beliefs concerning their children's feedback to reactions from external society that they might face in public, and how this might influence their performance.

Some of the mothers talked about societal influences and how their children's performance was modified; for example M19, whose son with moderate cerebral palsy used a wheelchair:

> Mother: *'The society outside, you see people look at him [with] a look that says "we don't want him! Why did you bring him here? Do you want to bother us?", and others overly sympathize with him, they adopt the sympathy policy: they approach them, and touch them, which is annoying! This thing annoys me a lot! It annoys me! I don't know, maybe it's only how I feel, or something like that, but I don't like, I don't like this look that really makes you feel ... or they come and ask you, I don't like that! It's enough, you saw him, that's enough! Especially because he looks very normal except for the lower parts, so it's enough just leave him, don't bother about him'.*

Researcher: *'You feel annoyed by people for yourself, or for him?'*

Mother: *'Both, my child understands! If I look at the other mothers for example whose kids don't understand, or are not aware of things around them, I have mercy on them. They should have mercy on [the mother], she went out to entertain her kid, and herself, why do they bother her? Have mercy on him and on her! For example, once a man in Giant's amusement park said: "You bring him here to annoy the Muslims with." He means with their chair!! What damage will it bring to him!! If it wasn't for shame, I would have told him "you bastard!" it was on the tip of my tongue'.*

This mother refused sympathy from society and felt that her child was sometimes not welcome in public. She was angry and defended her right to enjoy herself with her son, describing the difficulties they had going out because of public feedback. This might have limited her son's opportunities to socialize in confidence and might also have impacted his independence development. M19 also mentioned on another occasion that her child could use the walker, but avoided it in public because of his low confidence. She said that because her child understood people's words and might also have recognised sympathetic looks, he might have turned away from using the walker in front of people. She realised that

society might have had a direct relationship with her child practising and developing independence.

However, some of the mothers mentioned that they were not influenced by society. For example, M6 focussed on training her son and developing his personality. She said that she did not pay attention to people when she went outdoors with her child; rather, she focused on him and his practice, and therefore believed that it did not influence his development. Most of the mothers – on many occasions – mentioned that they were annoyed by society judging their children, and some also mentioned how this might have affected their children's chances to engage in outdoor activities. However, it was found that the degree of societal influence depended on the weight the mother placed on it and how she dealt with her child's practice while outdoors. Therefore, the mothers' beliefs regarding external society's influence would have contributed to shaping their beliefs regarding their children's performance and training to be independent.

8.4 Conclusion

Factors were found in the mothers' interviews that might have helped to construct and influence their beliefs regarding their children's potential and training to be independent. The mothers believed that these factors played a role in influencing their children's performance, ability and training. Analysing and interpreting them assists in understanding how the mothers' beliefs regarding their children's ability and training to be

independent were constructed. These beliefs were found to be related either to the mother, to the child, or to external factors.

The part of these beliefs represented by the first theme were ‘related to the mothers’; most mentioned negative feelings regarding their children’s cases, while some talked about relief from self-blame. In addition, almost all the mothers spoke about their children’s future; the majority were optimistic regarding improvement, although many others preferred to try not to think about it. These beliefs may have influenced the mothers’ motivation during the training of their children, and therefore contributed to shaping the mothers’ beliefs regarding it. It was also found that some of the mothers had health problems that might have hindered them during the training process and influenced their priorities. The behaviours of the mothers were captured within the data as well. Some were physically and psychologically protective towards their children, which in turn appeared to influence their children’s performance and might have affected the mothers’ beliefs in regard to their children’s training and how they believed independence could be achieved. Some tended to be firm with their children, while others relied on other people, for example the therapist, for the training. Some of the mothers talked about the efficiency of their own efforts during the training process, reflecting their convictions about how independence could be achieved, and some mothers talked about being patient, which provided information about their expectations during the training process.

The second part of these beliefs was related to the children's characteristics; most of the mothers believed that their children's wishes and negative behaviours played a role during the training process. This revealed the mothers' beliefs about their children's roles during their own training process and their beliefs in their children's responsibilities in contributing to the training. Furthermore, some of the mothers recognised that their children's improvement provided them with hope and influenced their feelings and motivation to train, which might have influenced their convictions regarding their children's potential to develop independence and in turn the training process itself. A few mothers also believed that their children's health problems, such as muscle shortening, joint stiffness, or seizures, influenced their children's performance. It is possible that this influenced the mothers' beliefs about their children's training. Most mothers talked about the speaking ability of their children; the majority of them believed it played a role in their independence, and some believed it encouraged their children's social abilities and readiness to be separated from them. These beliefs were interpreted as factors that were related to the children, and were assumed to impact the children's performance and ability, and also appear to have affected the mothers' beliefs concerning their children's potential and training to be independent.

The third part looked at the mothers' beliefs about external factors. Most talked about the extended family's involvement, recognising their influence on their children's performance, while some of the mothers valued their family's support in the training of their children. Notably,

most of the mothers were annoyed by certain reactions to their children from within society. Some of the mothers believed it affected their children's performance, while others chose to ignore it, thereby reducing its impact.

The analysis and interpretation of the mothers' beliefs in this chapter revealed that some beliefs that were related to the mothers themselves, their children or their surroundings appeared to contribute to the construction of the mothers' beliefs regarding their children's potential and training to be independent.

Chapter 9: Researcher Reflexivity

In this chapter I will demonstrate how a reflexive approach was applied during the research process, and how reflexivity was involved in the context of the analysis and reporting of the findings. The research limitations and strengths will be highlighted, providing contextualisation of the final results. The chapter will begin with an explanation of my understanding of reflexivity, then how my position as a researcher, physical therapist, mother, Saudi, and Muslim contributed to the research process.

9.1 Reflexivity

Researcher reflexivity is a specific strategy that is suggested to improve rigour in qualitative research (Hansen, 2006). Lincoln et al. (2011) define reflexivity as “the process of reflecting critically on the self as researcher, ‘the human as instrument’” (2011, p. 124). Tracy (2010) believes that the honesty and authenticity of the researcher creates self-reflexivity, where the researcher becomes frank regarding their strengths and weaknesses. Reflexivity requires the understanding that the researcher is part of the study setting and acknowledges the recognition of their personal background, training, and beliefs throughout the research process (Hansen, 2006). Researcher reflective practice is a process that helps to gain insights into the researcher’s self and practices by learning from their experience (Finlay, 2008). A

declaration of the researcher's position or reflexivity is important to provide evidence of the research quality; it is taken as self-evident, and suggested that if done well can be a powerful tool to examine practice (Finlay, 2008; Merriam, 2009; Thorne et al., 2004). Researcher subjectivity is not considered a deficiency in research when it is employed as a resource to enhance the research discipline (King and Horrocks, 2010). Reflexivity compels the researcher to clarify their biases and experiences, and declare their assumptions and interpretations regarding the study under investigation (Hansen, 2006; Merriam, 2009). In this study, acknowledgement and critique of the researcher's position and reflexivity has been used to enhance the study's rigour and credibility.

9.2 Pre-research stage

In qualitative research, the researcher's 'personal lens' is involved, from the generation of the research question until the final write-up (King and Horrocks, 2010). My background as a paediatric physical therapist gave me the chance to meet with mothers during their children's physical therapy sessions and begin to form impressions about their thoughts regarding their children's status.

My MSc dissertation explored independence in Saudi Arabian children without physical and learning disabilities (Alkhudair and AlEisa, 2014). The study examined the applicability of the outcome measure the Pediatric Evaluation of Disability Inventory (PEDI) among Saudi

children. This was through interviewing mothers of non-disabled Saudi children using structured interviews then comparing their scores with the original US children's scores. A key finding was the delay of the Saudi children's independence abilities, compared to American standard numbers (Haley, 1992).

Within the findings there were possible explanations to understand what mothers thought about their children's independence (see Introduction, Section [1.4.4]). This led me to consider the idea that the mothers' thoughts and beliefs might have had an influence on the children's independence. However, because the research used structured interviews, it was not possible to ascertain in-depth knowledge of the mother's' thoughts and beliefs and interpret it to get more understanding (Alkhudair and AlEisa, 2014). Utilising the PEDI as an outcome measure that examined the functional skills of the child in three domains (self-care, mobility, social activities), drew my attention to the importance of independence in evaluating the performance of children with cerebral palsy; each item from the categories of self-care, mobility or social abilities was evaluated according to the level of independence (Haley, 1992). The child's score on each item depends on the mother's description of her contribution to assessing the child while doing any of the tasks that represent the items. For example, while evaluating the self-care domain, in order to asses tasks like (eating, grooming, dressing, etc.) the score is decided according to the mothers' explanation of her child's level of independence and her contribution; this small discussion although not sufficient provided some

clues about the mothers' thoughts regarding their children's independence and how it might have role in the children's levels of independence.

My experience during my MSc degree research contributed to guiding my considerations whilst reviewing the literature of this study. It helped me to expand my understanding of independence and focus on studies that discussed different aspects of the independence of disabled children, for example focusing on self-care and its items, mobility and its items, and social activities and its items. This helped in identifying the knowledge gap clearly, and helped to formulate my research question. Moreover, my previous experience while interviewing mothers provided an impression of the mothers' thoughts about their role in the development of their children's independence; this in turn motivated me to explore their beliefs in this area. My clinical experience in rehabilitation centres provided me with a conceptualisation of children with cerebral palsy and their abilities and training. All of this led me to the research question that aimed to identify parental belief systems regarding the independence of children with cerebral palsy among Saudi mothers.

9.3 Theoretical perspective

When I started exploring the theoretical perspectives that were compatible with the research question, I aimed to make them correspond with my ontological and epistemological position. Initially, I

focused on my position towards the construction of reality and knowledge within my research question, which aimed to identify 'parental belief systems regarding the independence of children with cerebral palsy'. By thinking of the meaning of the 'beliefs' in general and reading the literature on how 'beliefs' are involved in people's lives (Domènech et al., 2010), I came to recognise the occurrence of the 'beliefs' on their own, irrespective of whether they differed from one to another, or if I agreed or disagreed with them. From my perspective the presence of an individual's 'belief' is essentially to be deemed one reality, therefore, 'parental beliefs' were considered to be the reality part of the research question. This standpoint corresponds with the theoretical perspective of critical realism (Danermark et al., 2002).

Critical realism views reality as independent and external but not directly observed; it can explain this reality by focusing on the causal relation between social structures (Saunders et al., 2009). Through my experience of meeting mothers in physical therapy sessions I recognised that the way they deal with their children's development of independence might be a product of 'beliefs' that are considered here to be an 'external reality'. In critical realism knowledge is considered to be constructed through different perspectives. However, my understanding of both reality and knowledge within my research question was still a little confusing; I had a clear understanding of the 'reality' part, but the 'knowledge' part was still unclear to me. Since I knew that knowledge in critical realism is about constructing a number of perspectives, this

confused my understanding of whether the ‘beliefs’ constituted the reality part or the knowledge part.

Therefore, I did not hesitate when my supervisors recommended that I contact an expert in critical realism from the School of Health Sciences, Dr. Alison Edgley. I arranged a meeting with her and we had a fruitful discussion that clarified my understanding of critical realism and how to acknowledge the presence of reality and knowledge in light of this approach. She agreed with me that the ‘beliefs’ of the parents represent the reality part of the research, and clarified that the data collected from the mothers could contribute to constructing my knowledge about ‘parental belief systems’. We also discussed the idea that the parents’ interpretations of their beliefs, along with my own interpretations would be involved in constructing the knowledge.

Deciding upon a suitable methodology was not a direct process, since the research question had not been designed to fit a specific research methodology. The literature review revealed that the research question did not fit any of the well-known qualitative methodologies (grounded theory, phenomenology, and ethnography), and I found a generic qualitative approach (Merriam, 2009) to be more appropriate. However, to address the research question it was essential to obtain a deeper understanding of the parents’ beliefs, which required interpretation of the findings, and this corresponded with the interpretive description strategy (Thorne, 2016).

9.4 Pre-data collection

After refining the research question, and during the preparation of the research method, my professional background as a physical therapist and the knowledge gained from my previous research in normally-growing child standards were influential in formulating the first version of the interview guide. From my previous research in the applicability of PEDI (Alkhudair and AlEisa, 2014), I had learned that the focus in evaluating child independence appears to lie in three domains: self-care, mobility, and social function. Therefore I designed the first interview guide to focus on the children's skill performances, specifically those skills that related to the three domains and could provide information about their independence. These were: self-care (eating, dressing, toileting, grooming) and mobility (creeping, crawling, walking and transferring in general). My knowledge of these skills came from my professional and research backgrounds. However, after analysing the initial pilot interviews I recognised that asking the mothers directly about their children's skills did not provide any understanding of their beliefs about independence. This part of the first pilot interview was excluded from the sample:

> Researcher: *'Ok, to have more understanding about (child name) and his independence at home, I want you to tell me about his routine starting from waking up? What happens, lets talk about weekdays?'*

Mother: *'He wakes up then I shower him …' (silent)*

Researcher: *'Who wakes him up?'*

Mother: *'I do… I change his clothes, give him his bag and let his father take him school.'*

Researcher: *'Can you give me details about the things you do with him, like when he wakes up and wants to go to the toilet; what happens, how does he go?'*

Mother: *'I take him.'*

After the preliminary analysis of this interview and subsequent pilot study interviews, it was felt that asking the mothers directly about their children's skills did not help elucidate data about their beliefs regarding their children's independence. Analysing the pilot interviews required me to stop and think of the reasons behind the poorly-revealed data. My modest interviewing skills and the questions asked were insufficient to access the mothers beliefs. Questions in the second and final version of the interview guide were based on supervisor feedback and reflection after the pilot interviews, alongside preliminary analysis and field notes. I used the notes in my reflexive diary and feedback during the interviews to form the questions that I believed would best address the research question. This is part of the field note I wrote after the sixth pilot interview:

After this interview I can say that number of mothers might be worried that the surroundings can influence their children. Today the mother drove my attention that she several time go back to the talks about their extended family and how her in-laws are supporting while her family are not supportive and appear to believe that this support has impact on the child. She mentioned her child feeling she probably believes that his morals might influence their performance or abilities I don't know.

This note supported the addition of questions regarding the mothers' beliefs about whether the children's social surroundings have an influence on their abilities, and how the mothers link the children's feelings with their ability to develop independence. For instance one of the mothers M16 said

'on Fridays she goes to her fathers' family house. I feel good because she plays there and has fun; she is welcomed, while on Saturdays I take her to my family house. She becomes upset because none of the children want to play with her and make fun of her, then she cries and avoids playing'.

This provides knowledge that the surroundings might have a role in the child's performance of activities that might be related to independence; therefore this area might worthy of further exploration.

The pilot interviews were time consuming, especially because of delays in obtaining interview translations, which I needed to allow my supervisors to evaluate the quality of the interviews. However I feel that the whole experience was beneficial; analysing these interviews and discussing them with my supervisors, reading my reflexive diary and extensively studying to improve my interviewing skills expanded my understanding on how to obtain rich data. I learnt that careful analysis of the interviews helps in the development of questions that guide the researcher to obtain diverse information, which when gathered together might be useful in examining the research question. For example, at the beginning of my research, I thought that if I knew the mothers' beliefs about developing skills like eating, grooming, and toileting it would lead me to their beliefs regarding independence. Later I realized that even the mothers' understandings of independence itself were not unified, and that their thoughts or beliefs about independence were not only linked with those skills directly, they were also linked to related areas. For instance, independence in social activities skills appeared to be linked to the child's personality development. Therefore, when interviewing the mothers to understand their beliefs I needed to take these considerations into account.

9.5 Data collection and analysis

Atkins and Murphy (1993) provide three stages for the reflective process. I would like to outline these stages in light of my experiences

of reflection during data collection and analysis. The first stage is when the researcher or professional is aware of *uncomfortable feelings* and thoughts. I experienced this in the initial interviews whilst, listening to the mothers, I started to think about how the data was going to be analysed to reveal their beliefs. Because of my lack of experience, I often hesitated when asking a question to be sure not to influence the mothers' answers. For example while talking about the child's daily routine I was confused whether to ask about each skill and the mothers' level of support or to wait for the mother to talk about it by herself. Moreover, at the beginning of the interviews I used to introduce myself as a physical therapist and researcher, feeling that I had to mention my role as a researcher to justify doing the interview. I also felt more comfortable being open about my background as a physical therapist. Validating the choice to adopt both identities had both strengths and weaknesses, and this sometimes created a conflict for me; it was difficult for me to refrain from commenting when the mothers showed confusion or a lack of knowledge about training, or understanding their children's case. I understood that the mothers' permission had been given for interviewing to explore their beliefs, and they had not agreed to meet me for advice or consultation about their child, and I had to respect that this was also not part of the purpose of my study. I did not consider it ethics to involve myself with, or comment upon, the centre's training programme, and this was not covered by the ethical approvals I had obtained from the University of Nottingham and the centre.

The second stage includes *critical analysis* of the feelings and knowledge; it was during this stage that I actively worked at being reflective. I recorded my thoughts and notes in a reflexive diary (field notes) during the research process, immediately after each interview either before leaving the room or on the same day at home. Sometimes I added more notes when listening to the interviews during data analysis. I focused on: 1) my impression of the mother during the interview, and the message she wanted to deliver. For example, when she talked about her child's potential to develop independence did she want to provide a message about her thoughts concerning the future, was she optimistic or pessimistic, or when she described the child's training routine did she want to provide a message about her motives or knowledge concerning the training; 2) any areas that were worth more exploration in future interviews. For example, during their explanation of their child's performance of different skills, some mothers used expressions that reflected their belief in the child's desire to develop. This was often a small hint during the mothers' interviews that opened the door for more exploration of their beliefs; 3) the amount of new topics that were discussed in the current interview, and data saturation. 4) finally, I recorded my impressions of the interview, and my interviewing skills. Here is an example of a reflexive note that I wrote after meeting M3:

> *One of the things that drives my attention today is the mothers' mental health, it was like mix of depression, guilt feeling and desperate. At the same time she wants to answer me an ideal*

answers. My thoughts were she might have problem in accepting gradual improvement of her child, she said about her child trial to dress or to eat by herself to 'she is annoying me'. Because the child was trying to dress but can not do it, or eat with mess, the mother show perfection in general and find her child trial to do the skill by herself obstruction of their routine, the mother also mentioned that she is frustrated and she look like actually and mentioned that she might transfer this to her daughter. The mother also look religious and this is constricting her to think and speak positively to avoid something religiously disapproved.

The two rounds of interviews appeared to help me build relationships conducive to disclosure with the mothers, and this was reflected in the generally relaxed atmosphere of the second round interviews. In the first interviews I discovered that most mothers wanted to talk about their children's story and the first time they found out about their child's disability. Although this was not part of the target data, I realised that talking about it would increase the mother's trust and relaxation during the interview. I also believed that some mothers, in both rounds of interviews, found an opportunity in our conversation to vent frustration about the lack of support in their surroundings or services, or to express their anger regarding society, family, or the father. This was not unexpected given my knowledge of the conservativeness of Saudi society and people's general behaviour in such a context. Data were only

collected from the mothers, because having access to the fathers was difficult due to gender segregation (see Section [3.3.2]). I felt, however, that this did not affect the depth of the data, because acknowledging my position as a Saudi woman living in the same society I understood the mother's role in taking care of the children more than the fathers.

For a better understanding of why a researcher would offer a particular interpretation of the data, it is essential to uncover the lens they used to view this data (King and Horrocks, 2010). This is not to differentiate between it and the research expectations, but rather aims to capture how the researcher's assumptions influence the research findings (Maxwell, 2005). In the current research, data analysis took place primarily after each interview, and I used the feedback from the interviews to gather the group of codes into a more meaningful one that reflected the data. Moreover the primary analysis of the entire first round of interviews and my reflexive notes were used to develop the interview guide for the second round interviews. During data collection I reflected on my position and experiences following Gibbs's Reflective Cycle (Gibbs, 1998), as shown in Figure 8.1 below.



Figure 9.1. Gibbs's Reflective Cycle. (Gibbs, 1998)

This model provided me with a structural way to document my reflections throughout data collection. It begins with describing the situation and ends with forming an action plan for the future; in each step of the cycle there are questions that help to know what to document. Reflecting on my experience during data collection allowed me to understand the situation and how to deal with similar situations in the future. This corresponds with my understanding that reflecting-in-action is when the researcher examines their experience as it happens (Finlay, 2008). An example of following Gibbs (1998) from my reflexive diary after interviewing M5 can be found in Table 8.1 below:

Description	During the interview the mother was talking about her child's delay in progress although of training and that he is still creeping and describes what the physical therapist do and advises the mother to do, I did not share my opinion. Then after the interview finished the mother asked for advice to improve her child, and I said that I would discuss this with the child's physical therapist.
Feelings	When the mother was describing the child rehabilitation program, from inside I wasn't in agreement that while the child was still creeping to train him to walk, for me, I believe in staging and I think the child must pass each stage to strengthen the muscles needed for the next stage, creeping then crawling then kneeling then standing then walking. And I was hardly able to stop myself from interrupting her. Also, when the mother asked for advice I was shocked and confused about what to say and I believe that was obvious, I did not want her to feel that I didn't know what to advice to give and not to feel that I am mean in refraining from giving advice while she provided me with time for the interview.
Evaluation	The bad thing is, that even I knew that I have to separate my role as researcher and physical therapist, but I did not prepare myself to have a fixed answer for such a question. And that I told her I will discuss it with her physical therapist while I can't because I did not know if I am allowed or not and not sure of the therapist feedback. The good thing about this experience was one of the early pilot interviews and taught me how to react in the future.
Analysis	I realised that I have to be careful while interviewing the mother, if I am going to introduce my identity as physical therapist and researcher the mother will not understand that while I occupy one of these identities I have to freeze the other one. Therefore I have to expect these advice requests.
Conclusion	I don't think there is anything else that I can do, I don't believe it is wise to explain to her that while I know what to advice to give to her but I can't. I am not sure if she is going to understand this, at the same time I felt bad that I promised her something that I can't do which is contacting

	the therapist.
Action plan	I am thinking in the future not to allow the mother to express in details about their rehabilitation plan to prevent her from expecting me to contribute. Also, if the mother ask me direct question I will mostly say I am not allowed to advise, as I do not know the child's detailed diagnosis and it is not fair to advise from her verbal description.

Table 9.1. Example of using Gibbs (1998) from my reflexive diary.

The third stage of Atkins and Murphy's (1993) reflective process is the *development of new perspective*. This occurred more during the data analysis phase, while I was analysing the collected data and reflecting on my experiences. The iterative data analysis in this study allowed reflexive visiting and revisiting of the data, and the connection of it with my experiences, thereby enabling progressive understanding (Thorne, 2016).

During data analysis, it was helpful to me that as a mother I was able to have some access to understanding the mothers' explanations regarding their children, considering the individual differences between parents in child rearing. My professional background as a physical therapist helped me to understand the children's cases and abilities from the mothers' descriptions, and to some extent, to recognise their efforts in training. After finishing the coding of the data, and starting to group the interpretive codes into themes, there was an option to group them according to the '*ladder of engagement*' or '*mothers' understanding of independence*'. King and Horrocks (2010)

recommended, as part of the reflexive practice, that the representation of the data should be directed at a particular audience. Because of my background as a physical therapist and my intention to propose this research to the physical therapy community, I chose to group the data according to the '*mothers' understanding of independence*', because I thought that this would reflect the physical therapy lens in analysing the maternal beliefs more than any other grouping.

Also, during data collection, my identity as a Saudi Muslim woman helped me to understand many details that reflected Saudi society and culture or the mothers' Islamic beliefs, and I used this in my analysis and interpretation of the data. However, during the preliminary analysis, being immersed in the same culture and religion prevented me from immediate recognition of the dominance of these religious and cultural beliefs over other beliefs. Recognizing the cultural influences was much easier; although they are widespread in society, they were easier for me to identify, which might be because I do not practice it in my close environment like gender segregation. On the other hand, although I noticed the presence of religious beliefs, I did not recognise their dominance until I had several discussions with my supervisors that made me return to the data. This might also emphasise how these beliefs can be deep, impacting and controlling unconsciously. I had to work on 'stripping myself' from my Muslim identity, for instance, my attention was not immediately captured by the mothers' use of many expressions that related their children's development to 'God's will', because this kind of expression is common in Muslim speech. Being

Muslim, having the same beliefs, and also using the same expressions myself prevented me from recognizing the rich presence of religion within the mothers' explanations, showing their faith, hope and acceptance.

I had to use my awareness to separate my current task as researcher from my religious and cultural beliefs and use a critical lens in analysing and interpreting those beliefs. Although my background helped me to access the mothers' beliefs during data collection, it caused more difficulty while I was analysing the data.

Being Saudi also helped me to understand the four different Saudi accents I was dealing with, which were all totally different from classical Arabic. However, every time I analysed the data I had to listen to the audio recording, because when reading the transcripts of these Saudi accents it was difficult to recognise the real meaning. I believe that although this was time consuming, in my opinion it aided in providing better analysis, and helped me to select more comprehensive and meaningful codes.

9.6 Conclusion:

Documenting analytic reflection using a diary is a way to capture reflections; it is like a confessional tale about the researcher's background, complaints, temptations, and opinions (Tracy, 2012). This chapter demonstrated the reflective practice that was used during the research to enhance its quality. Reflexivity allowed me to understand my position as a researcher, while at the same time acknowledging my

background as a Saudi Muslim mother, and physical therapist. Using reflexive practice helped me to recognise the strengths and limitations of my study, which will be demonstrated in the next chapter.

Chapter 10: Discussion and conclusion

10.1 Introduction

The findings of this study contribute to the research on parents' beliefs concerning their children with cerebral palsy. The findings provided in-depth qualitative data about maternal beliefs regarding independence. It also showed that these beliefs are related to the mother's surroundings, mainly her religious and cultural beliefs, extended and close family, external society, her child, and so forth. All of this creates nested poles around the mother, which have different levels and quality of influence on her beliefs. In order to address these relations it was beneficial to view the findings from a broader socio-ecologic perspective that can significantly support the idea of the influence of the surroundings on maternal beliefs (Bronfenbrenner, 1977). The socio-ecological model was selected as an explanatory framework to explain the relationships among maternal beliefs and the interaction of the mothers with their surroundings. The complex relation between the mothers' environmental surroundings and their beliefs that revealed from the findings was not expected before collecting and analysing the data, therefore, that the socio-ecological model was not highlighted earlier in the literature review. This chapter provides further depth in understanding the major findings. However, a brief introduction of the socio-ecological model and how it can help to explain the current findings will be given first in this chapter, followed by a discussion of the findings in light of the socio-ecological model. The chapter then will

provide an explanation of the study's limitations, its implications for practice, and recommendations for further research, followed by the conclusion.

10.2 The socio-ecological model

The socio-ecological model provides an overarching framework that helps in understanding the interrelationships between personal and environmental factors, particularly the personal relationships within social, institutional and cultural contexts (Stokols, 1996, Bronfenbrenner, 1977). The socio-ecological model is based on three assumptions (Bronfenbrenner, 1979): first, the individual is an active player who influences the environment; second, that the environment forces the individual to adapt according to the surrounding circumstances and restrictions; third, the environment consists of several entities that are embedded in reciprocal relationships. Each level is represented using micro, meso, exo and macro systems, as shown in Figure 10.1 below.

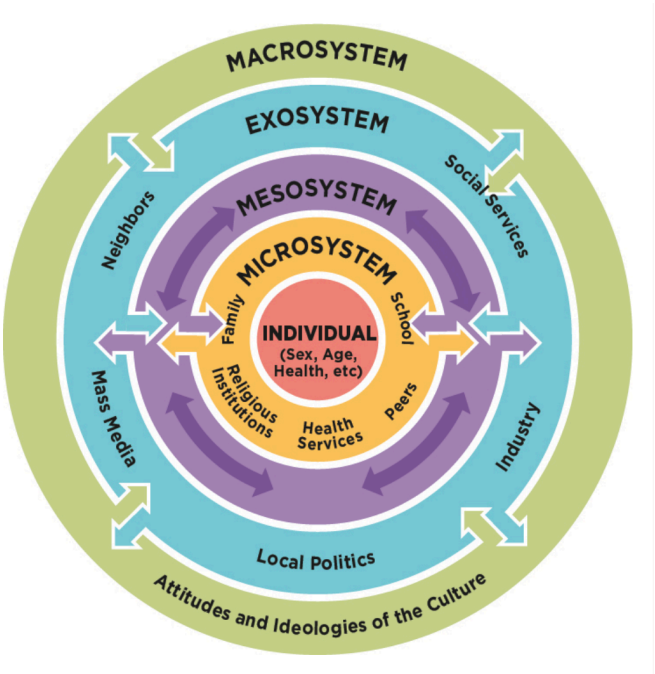


Figure 10.1. Socio-ecological model (Bronfenbrenner, 1979).

10.2.1 Applying the modified socio-ecological model to discuss the findings

The mothers' beliefs of children with cerebral palsy are represented at the centre of the model and surrounded by environmental levels as shown in Figure 10.2. Each level of the mother's surrounding environment will be explained to clarify its significance for the findings of this study (Bronfenbrenner, 1977).

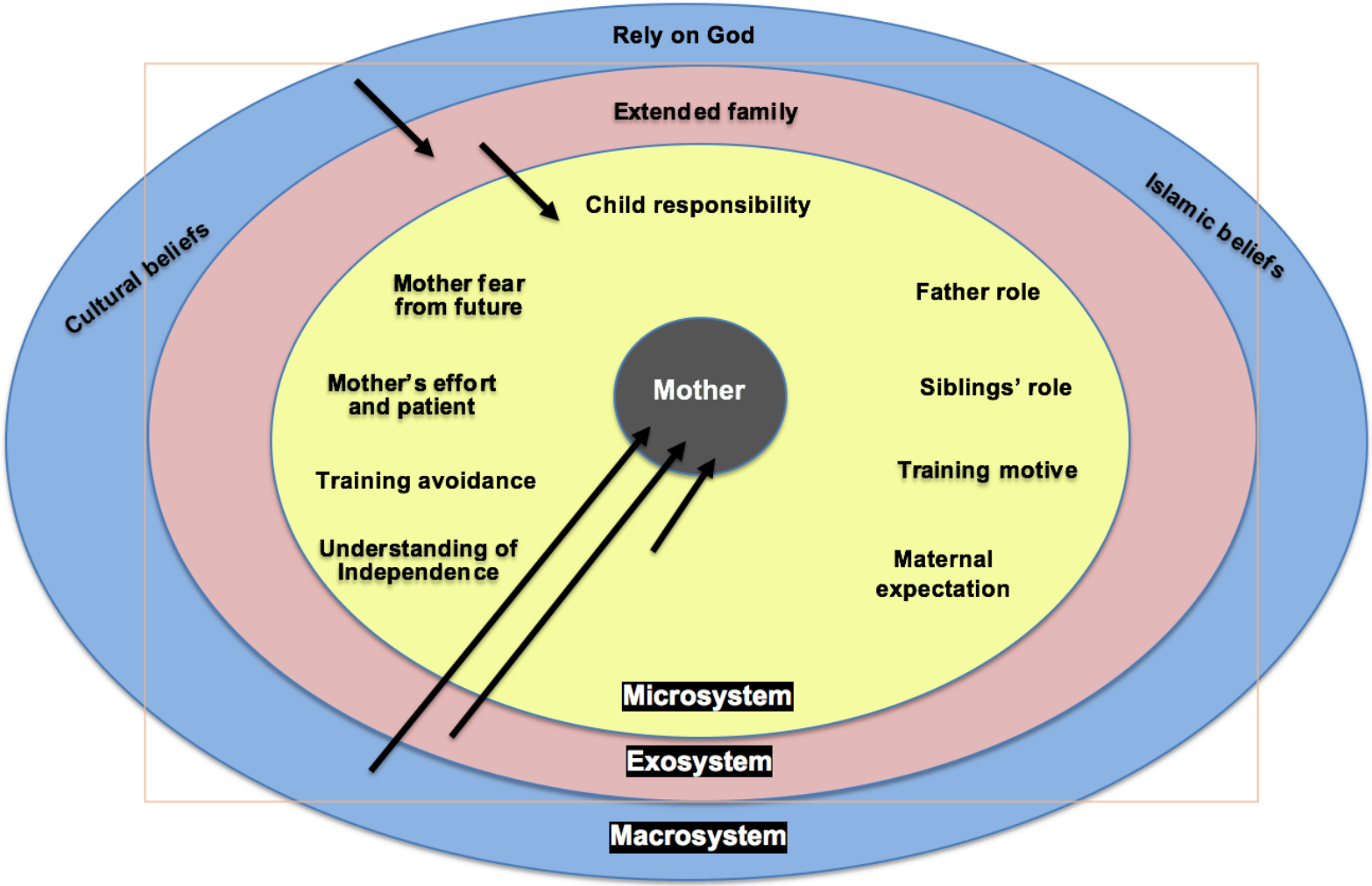


Figure 10.2. Modified socio-ecological model representing mothers' beliefs about their children's independence.

The first level is the microsystem, which consists of the pattern of activities and interpersonal relationships that the mother experiences in her immediate environment. This includes her relationships with her disabled child, other family members (the child's father and siblings), peers, the professional rehabilitation support system (therapists, rehabilitation centre, hospital and so forth), and mosques. Microsystems represent beliefs that concern the direct relationships involving the child in terms of the understanding of the child's independence. It also includes the expected functional abilities, motives, and precautions while child training that result from the immediate relationship between the mother and the child. In addition, the mother's beliefs regarding family members are revealed in the mother's interaction with others, such as the therapist, fathers, siblings and rehabilitation centre. The socio-ecological model clarify how The developmental outcomes of the maternal beliefs are influenced by the interactions within the microsystem (Eamon, 2001).

According to Bronfenbrenner's model, in the microsystem, the relationship between the mother and the surroundings is bi-directional, and this influence exists at all of the mother's environment levels. However, the current study demonstrates only the influence of the surrounding environment toward the maternal beliefs (Bronfenbrenner, 1977, Härkönen, 2005). This explains the direction of the arrows in Figure 10.2, pointing from the surroundings in each level toward the next environmental level and the mother.

The key to Bronfenbrenner (1977) theory is the interactions that occur between the settings at each level and the interactions between the environment levels. Identifying the relationships within the microsystem does not depend on the geographical location of each setting but the degree of their participation (Härkönen, 2005). This means that for instance, evaluating the influence of the father or siblings role does not depend on their location – as living in the same house as the mother – but on their degree of participation and involvement in the child's life.

When grouped, the relationships within the microsystem reflect the themes of the current research; 'maternal beliefs about their child's potential to be independent' (Chapter 6) and 'maternal beliefs about their child training to be independent' (Chapter 7). Moreover, some components of the theme, 'factors influencing beliefs' (Chapter 8), are also at the microsystem level, such as the mothers' behaviour and her mental and physical health as well as the child's characteristics.

The findings also showed that the extended family might contribute to maternal beliefs regarding the child's abilities and training for independence, which shows the interrelationships between the environmental levels around the mother. The extended family, which includes the families of both the mother and the father, might influence the mothers' beliefs regarding independence (see Chapter 8), are located in the exosystem.

The mothers' Islamic and cultural beliefs and her reliance on God are found in the theme 'maternal religious and cultural beliefs' (Chapter 5).

This represents the macrosystem, which is the outermost layer and influences all layers in the model, as shown in Figure 10.2 (Härkönen, 2005). It reflects the overarching patterns of the culture at all environment levels. Moreover, it is the cultural 'blueprint' that in part identifies the social structures and the characteristics of the macrosystem, which are transferred from one generation to another (Bronfenbrenner, 1977).

Explaining the current findings within the socio-ecological context help in tracing the surrounding influence toward the maternal beliefs, it also can contribute to the literature of the socio-ecological model for long term planning. However, the current findings do not fully map the socio-ecological model component, the mesosystem, which represents the relationship between the microsystem and the environmental setting (Bronfenbrenner, 1977). This cannot be represented according to the study findings, therefore it can be said that the study employs a modified socio-ecological model (Figure 10.2).

10.3 Macrosystem: Maternal religious and cultural beliefs

10.3.1 Religion as a coping strategy

Interwoven within and between the transcripts was the recognition that religious and cultural beliefs were predominant in the mothers' thoughts regarding their children's abilities and training to be independent. Whilst the importance of the religious beliefs of parents with disabled children (Crabtree, 2007a, Raman et al., 2010b, Landry et al., 2015, Gannotti et al., 2001, Bunning et al., 2017, Nazzal and AL-Rawajfah, 2017) and of

parents of children with cerebral palsy (Madi, 2014, Mir and Tovey, 2003) has been previously recognised in the literature, it has been in specific relation to their understanding of the meaning and causes of disability (Gannotti et al., 2001, Raman et al., 2010b, Madi, 2014) and emotional support (Mir and Tovey, 2003, Bunning et al., 2017, Crabtree, 2007a, Nazzal and AL-Rawajfah, 2017). In the current study, religious and cultural beliefs were considered to be of primary importance, as they informed the mother's beliefs concerning their children's potential and training to be independent, which emerged in the statements that reflected their convictions.

The data analysis revealed that the mothers linked their children's current improvement and potential to develop independence with *God's will, power,* or *mercy*. This finding reflects the Islamic teaching that God is the source of disease and health and that recovery will be rewarded by God according to good faith as described by Bhatty et al. (2009) in their review of disability in Islam.

In the current study, it was observed that the mothers linked their reliance on God with their explanations of their children's development, their assessments of their children's current abilities, and their future training plans. Novel findings emerged from interpreting these beliefs, based on Islamic teachings on one hand and the mothers' beliefs about their children's independence on the other.

The strong Islamic beliefs of mothers in this study provided support in their acceptance of their children's disability and also provided a coping strategy in a similar way to that described by Raman (2010). The acceptance of a child's disability was considered an aspect of Islamic belief, which also corresponded with the findings of previous studies in the literature (Madi, 2014, Crabtree, 2007a, Nazzal and AL-Rawajfah, 2017). The mothers in these studies believed that their disabled children were a gift from God and that accepting children's disabilities was part of being religious and being socially acknowledged as being a good Muslim. Madi (2014) study, which was conducted among Saudi children with cerebral palsy and their mothers, revealed their religious and cultural beliefs. However, these beliefs were focused on the mothers' understanding of the causes of cerebral palsy. Madi (2014) found that the understanding of disability by Saudi mothers was influenced by their religious beliefs and that their religious beliefs also worked as a coping strategy while raising their children. They also felt that their children might be cured because of their belief in God. Although there was no interpretation of this belief, the mothers might have believed that they would be rewarded for their faith in God by their children's improvement. Similarly, the findings of the current study indicated that the mothers believed that by thinking positively about God, they could be rewarded by their children's improvement, which was linked with the mothers' beliefs about their children's functional development. Interestingly, the idea that faith in God would be rewarded

by improvement in their children's condition is not limited to the Islamic faith but is true of a number of different religions (Bunning et al. (2017). In the current study the mothers frequently repeated their *gratitude to God* when they talked about their children's status and previous or future improvements. This belief can be linked to the Islamic teaching that showing and expressing gratitude to God would be rewarded by improvements, based on the Qur'an: '*If ye are grateful, I will add more (favours) unto you*' [14:7]. This belief also reflects the deep faith of the mothers that the more they felt and showed their gratitude, the more they would be rewarded by their children's improvement. This belief is likely to have provided hope and motivated the mothers to train their children. It was also found that when the mothers talked positively about the future, especially when coupled with the expression, '*God willing',* they were applying an important Islamic concept: *trusting God* and thinking positively about God. The prophet Mohammad said:

> Allah the Exalted says: 'I am as my slave expects me to be, and I am with him when he remembers Me. If he remembers Me inwardly, I will remember him inwardly, and if he remembers Me in an assembly, I will remember him in a better assembly' (Bukhari [7405]).

The findings showed that when a mother asked God to help her and heal her child, part of being a good Muslim was to believe that God would respond, which was reflected in her beliefs about her child's potential to be independent and her motives during the training process.

Several mothers expressed the belief that they were responsible to God for their children. In Islamic teaching, every individual must fulfil their responsibility. The prophet Mohammed said, '*All of you are guardians and responsible for your subjects*' (Bukhari [7138]). All Muslims believe in doomsday, when God will judge people according their good or bad deeds. Embracing this belief, and the mothers' recognition of their responsibility for their disabled children, might have motivated them to focus on caring for their children and training them to improve their independence levels. The literature review revealed that Islam clearly defines the responsibility of individuals and society. However, the findings in the literature do not show that mothers of children with a disability might be motivated while training their children to develop more functional abilities based on their belief in their responsibility before God. Because this belief is emphasised in the Islamic religion, it should be highlighted in exploring the maternal beliefs of Muslim mothers.

In addition, Islamic teaching emphasises working and expending effort, and not depending only on prayer. God said in the Qur'an, '*It is He who has made the earth manageable for you, so traverse ye through its tracts*' [67:15], which aligns with the findings in the literature that Muslim mothers choose both spiritual treatment and the physical management of their children's disability (Landry et al., 2015, Madi, 2014). Parents in these studies searched for medical, spiritual, and religious treatment at the same time. Landry et al. (2015) mentioned that the majority of the

mothers relied on religious (Buddhist) practices such as prayers as treatment for their children and that this worked alongside the rehabilitation services. The mothers in Madi (2014)study (2014) chose medical and rehabilitation treatment and also considered folk and religious treatment by prayers and healing with the Qur'an. In the current study while the mothers were talking about their children's training, they used their religious beliefs and reliance on God to support their plans in training their children to develop independence.

The mothers also mentioned patience, which is another aspect of Islamic teachings. Patience might be compared to acceptance, however, in the current study, it was highlighted in relation to the efforts the mothers made in training their children. Patience is strongly rewarded by God in Islamic teaching (Turfe, 1996): God said in the Qur'an: '*O ye who believe! Seek help with patient perseverance*' [1:153], and '*Indeed, the patient will be given their reward without account*' [39:10]. The current study's findings revealed that the mothers emphasised the importance of patience, which was linked with their religious beliefs in accepting their children's slow progress and being a good Muslim. Being patient and accepting what was given by God was believed to augment the mothers' good deeds, which would rewarded in heaven. Some mothers thought that their child might be their path to heaven. Similarly Raman et al. (2010) also suggested that some mothers believed that their children's condition was God's test of their patience, It can be understood from this finding that most of the mothers were influenced by their religious beliefs in developing their own beliefs

regarding their children's independence. Moreover they drew support and strength from them during the training process.

In the current study, a minority of the mothers accepted that their children's condition was '*what God wants*'; they accepted that their children's independence would be limited, and comforted themselves that this acceptance was part of being faithful. This finding corresponds with the findings of Raman et al. (2010b) that the mothers believed that if God wanted their child to be disabled, they could not do anything about it. This finding also provides insights into the ways the mothers might use their religious beliefs to justify negative sentiments about their children's independence. This was recognised to a certain extent in the current study. It was captured with two mothers, the first of whom has a child with mild cerebral palsy who could walk without support. The second one's child with moderate cerebral palsy moved using a wheelchair. While these mothers both had children with different abilities and different levels of independence they were both most likely frustrated and not motivated to train their children due to health and social circumstances. The findings in the literature also showed that having a disabled child was sometimes seen as a punishment from God rather than a gift (Raman et al., 2010b, Bhatty et al., 2009). However, this perception was not found in the current study. In contrast, in Islamic teaching, thinking or articulating thoughts that express despair are believed to reflect poor faith in the will of God and need to be quickly followed by a plea for forgiveness and a demonstration of gratitude to God (Omair, 2005). Several mothers referred to these negative

thoughts as coming from the Devil, and they felt guilty about following this way of thinking. These thoughts were not described in the literature on this area (Crabtree, 2007a, Madi, 2014, Raman et al., 2010b). In her study, Crabtree (2007a) found that mothers who believed that their children's disability was a punishment from God had negative thoughts about their children's future. The mothers in the current study did not express a belief in God's punishment, but some of them referred to their negative thoughts about the disability to the Devil without linking them to their child's future.

10.3.2 Gender difference

Whilst the current study did not specifically conducted to examine maternal beliefs related to their child's gender, other studies found that gender influenced the parents' beliefs about their disabled children. Nazzal and AL-Rawajfah (2017) suggested that parents believed that life was more difficult for disabled girls because they might be viewed as vulnerable, and a target of sexual abuse, which led the parents to lock the girl inside the home, using the excuse 'better safe than sorry' to justify their actions. In the current study, there was no agreement among mothers in their beliefs regarding disability and their children's gender. Some mothers believed that the condition was more difficult for the girls because they had fewer opportunities to participate in public activities than disabled boys did. However, some mothers thought that having a disabled boy was more difficult because he had to be separated from his mother in adolescence. In previous studies in Arab

societies, it was found that parents suffered extra emotional stress because of the stigma attached to having a disabled child (Nazzal and AL-Rawajfah, 2017, Crabtree, 2007a). However, a similar finding did not emerge in the current study, although this cannot be generalised for all Saudi society. Novel findings from this study showed that their children's privacy was also a concern, but it was an issue for both males and females, which could be connected to Saudi society's conservative dress codes. This finding frequently emerged because in some cases, it was a motivator for training the children in self-care skills, such as going to the toilet, and developing their independence. The cultural belief of ensuring privacy among some mothers in the current study sample motivated them to train their children to be more independent in some self-care practices to avoid being uncovered in front of strangers, including their own mother when they were older. The current findings showed that the mothers mentioned gender segregation when they talked about their motives for training their children to develop independence, especially boys, because at a certain age they are separated from their mother in family gatherings or at school. This cultural practice was not identified in other Arabic Muslim societies (Nazzal and AL-Rawajfah, 2017, Crabtree, 2007a, Raman et al., 2010b), possibly because this practice is more prevalent in Saudi society, Al-Aoufi et al. (2012) argued that some cultural perspectives might be influenced by religious faith, thus leading to actions that might incorrectly be attributed to religion. This finding indicated the importance

of highlighting the culture of the sample and its relevance for the religious beliefs of the participants.

In the present study, discussing mothers' religious and cultural beliefs helped to clarify the depth of these beliefs and how the mothers spontaneously integrated them into their promotion of independence. The findings showed that the mothers' religious and cultural beliefs were most likely the predominant influences on their beliefs regarding their children's independence.

10.4 Exosystem: Factors that influence the development of maternal beliefs

10.4.1 Fears of future

The mothers' psychology was found to influence their beliefs regarding their children's potential and training to be independent. One area that emerged from the data analysis was the mothers' thoughts about their children's future. This issue was also expressed in the literature by parents of children with various disabilities (Crabtree, 2007a, Nazzal and AL-Rawajfah, 2017, Taunt and Hastings, 2002) and parents of children with cerebral palsy (Lauruschkus et al., 2017, Whittingham et al., 2013). Most of the mothers in the current study were positive about the future in terms of the child's improvement, which was in agreement with Taunt and Hastings (2002), where the parents were generally positive – hopeful – about their children's future. In the current study, the mothers' positivity regarding the future was mostly linked with the

Islamic beliefs of relying on God and believing in a positive reward from God.

In the current study, some mothers mentioned that they were worried about the poor services that would be available to the children when they became older, and the limited chances of them finding a job that would fit their abilities. The mothers were also worried about poor support from the extended family, and their children's difficulties in socialising. These concerns were also found in studies by Whittingham et al. (2013) and Crabtree (2007a). The mothers were afraid of dying, and also of being forced to separate from their child. The same issue was raised by the mothers in Nazzal and AL-Rawajfah (2017), where the mothers were worried that in their absence, no one would be able take care of their child in the same way as they did. However, none of the previous studies mentioned that the mothers' worries were linked to their beliefs in training their children to develop independence.

In the current study, such concerns about the future influenced the mothers' beliefs about their children's independence. On one hand, mothers who were optimistic about their children's future believed in the feasibility of training their children to be independent and were therefore better motivated. On the other hand, the mothers who were pessimistic about their children's future were less inclined to train them to develop the skills that would enhance their independence. The mothers' statements regarding the future were linked to two religious beliefs, the

‘knowledge of the unseen’ (the knowledge of the future, which in Islam is reserved for God alone) and ‘thinking positively about God’. In Islamic teaching, only God knows about everyone’s future, therefore, when the mothers in the current study talked about the future, they linked it with God’s knowledge even if they did not clearly express it.

These details were essential in clarifying the depth of the mothers’ Islamic beliefs and explaining how they informed other maternal beliefs to form maternal belief systems. This finding confirms the relationships within the mothers’ environmental surroundings, where their religious beliefs in the macrosystem were related to their concerns in the microsystem.

10.4.2 Mothers’ effort and patience

The findings also showed that the mothers linked their child’s improvement with their own efforts during the training process. In Hinojosa and Anderson (1991b) study, the mothers talked about their participation in a home programme; however, they did not compare their children’s improvement with the amount of work they put in. They mentioned that the mother did her best if the exercises were enjoyable and not too difficult or stressful. They also felt that the physical therapist should do more in training the child to be independent. In Raman et al. (2010b), the parents did not believe they had a significant role to play in training their children, and they had little responsibility for it. By way of contrast, in the current study, the mothers mentioned that for their

children to have good results and develop independence, they needed to make an effort and be patient in training them. Trying and working hard were found to be factors that influenced their beliefs about their children's training; this is recommended in Islamic teachings.

10.4.3 Beliefs regarding child responsibilities

It was found that some factors that were related to the children themselves influenced the mothers' beliefs concerning their children's potential and training (Chapter 8). They talked about their children's wishes and desires as motives that played a role during their independence training. In several other studies, the children's own self-motivation was also found to be an influential factor during training (Tatla et al., 2013, Majnemer et al., 2008, Gibson et al., 2012). Gibson et al. (2012), for example, interviewed children with cerebral palsy and found that they were motivated to train to walk because they knew it was good for them and believed it was important; this was reflected in the efforts they made during training. Although this study did not consider the mothers' beliefs, its findings regarding the children's beliefs confirmed the current study's findings regarding the mothers' beliefs.

Majnemer et al. (2008) found that for children to be encouraged to actively participate in activities that enhanced their skill development and productivity, it was recommended to engage the child in activities of their own choice. Child self-motivation was found to be essential in

promoting motor and functional outcomes (Tatla et al., 2013). In the current study, the mothers appreciated the children's self-motivation in encouraging them to train, attempt and practice the skills that helped them develop their independence. They believed that the children's desire to achieve a skill was enough to push the child into training. This finding indicates the mothers' belief in the children's roles and responsibilities in developing their independence.

In addition, the mothers linked their expectations of their children's levels of independence with the child's chronological age and their potential to develop independence during the stages of growth. In the literature review, it was found that children with cerebral palsy usually decline in function as they grow physically due to increased body size, reduced activity, changes in spinal alignment and imbalance in physiological resources (Haak et al., 2009, Tosi et al., 2009, Hanna et al., 2009). Conversely, in the current study many mothers were convinced that some development of independence would occur without training as the child grew. This belief might have been due to their general knowledge or their experience of their own child's development as they became older. However, this finding also reflects the mothers' belief in an external component that would affect their children's development.

10.4.4 Role of extended family

The findings of the current study showed that the mothers perceived their extended family as having a role to play in the children's training process. The role of the extended family was also examined in several

studies. Lauruschkus et al. (2017), Mir and Tovey (2003), and Landry et al. (2015) found that support by the family was very important in helping parents cope with their children's disabilities, both emotionally and during the training process, and it helped them to think positively. Milbrath et al. (2008) emphasised the importance of the extended family and found that mothers became closer to their families in order to gain their support. This finding corresponds to the current study, where some mothers expressed their appreciation for their family's support, whether it was emotional, financial or physical.

In Milbrath et al. (2008), the mothers also mentioned that they felt guilty when they were asked why there was a disabled member in the family. Similarly, in Nazzal and AL-Rawajfah (2017) and Patel et al. (2017), the mothers mentioned that they were pressured by their extended family to hide the child because the disability would have a negative social influence on the family. The current study rarely found that the mothers believed their families to have been stigmatised for having disabled children. However, some mothers believed that their families had a negative effect on their children's development, because they spoiled the children or underestimated their abilities, which caused both the mothers and children to be frustrated. However, the majority of the mothers in the current study believed in the value of the presence of their extended family's role and the importance of their support. Some mothers with absent fathers believed that the family filled the gap left by the father, and mothers with long working hours left their child in the

care of their grandmothers for part of the day. The mothers' extended family is located in the exosystem, in the environmental level. The influence of the extended family on maternal beliefs about training their children, which is located in the immediate microsystem, confirms the interactions within the mother's environment levels. This theme showed that the mothers' beliefs about training their children to be independent were most likely to be influenced by the surrounding environment as well as by other factors related to them and to their children.

10.5 Influence of the microsystem

10.5.1 maternal understanding of independence

The findings showed that the mothers expressed their beliefs in their children's ability to develop independence in different ways. In this study, the mothers did not agree on a single understanding of 'independence', which compares well with the findings of previous studies conducted with able-bodied children (Suizzo, 2007, Kusserow, 1999). Although the parents stated that independence was an important goal, they did not agree on a unique meaning of 'independence'. However, in other studies on able-bodied children, being independent was defined as being able to walk without supervision and being able to defend themselves (Kusserow, 1999, Veitch et al., 2006, Janssen et al., 2016).

In the current study, some mothers stressed the importance of developing the mental abilities of their children because they felt that

this would enhance the progress of their children's functional skills. This finding aligns with the findings of previous studies in that the self-care capabilities of children with cerebral palsy were more advanced in relation to the intelligence level of the child and that children with intellectual disabilities were found to be more difficult to manage (Nazzal and AL-Rawajfah, 2017, Smits et al., 2011). In the current study, mothers of children with higher levels of understanding recognised that their children were able to understand their guidance. In developing their children's independence, some mothers focussed on ensuring that their children's mental abilities were in line with their functional abilities. This finding provided insight into an aspect of the mothers' beliefs about how their children's independence could be achieved.

In the current study, some mothers focused on the physical development of walking as a means of achieving their children's independence. They also believed that walking would improve their children's social functions by allowing them to move freely when playing with their peers. The same beliefs were expressed by mothers in several previous studies (Wiart et al., 2010, Gibson et al., 2012, Lauruschkus et al., 2017). In a study by Gibson et al. (2012), the mothers believed that walking was a goal in itself. However, they did not indicate an understanding of 'normal walking'; for them, walking had both functional and symbolic values. The current findings showed that walking was also a goal of some mothers. However, mastering independent walking was emphasised mainly for its social value and to

ease training in self-care activities such as going to the toilet, which would lessen the burden on some mothers. In the current study, the mothers' explanations provided knowledge about how they related their children's ability to walk to their children's independence. They linked them with developing social skills and other self-care abilities.

In the current study, the mothers prioritised the aspects of independence that they believed their child needed; however, they did not agree on the priorities. The literature review revealed that in previous studies, mothers prioritised walking and physical activities (Gibson et al., 2012, Wiart et al., 2010). However, at the time of writing, no study had investigated the differences in parents' priorities in developing their children's independence. The findings revealed that these mothers prioritised developing some skills over others. Their priorities were set according to either the child's normal growth milestones, weaker skills, level of attachment to the mother, or the child's own wishes. The reason for the order of priority was not intentionally explored in this study. However, in interpreting the data and linking the mothers' statements, it was found that mothers who did not plan for separation from their children did not prioritise self-care skills and vice versa. The findings also showed that when the mothers prioritised the child's social activity, they also prioritised walking so that the child would be able to play with their peers and siblings. Discussing the parent's priorities regarding their children's independence development with the rehabilitation team was recommended in the

literature (Wiart et al., 2010). Furthermore, according to the current findings, professionals should consider that their understanding of independence might not concur with the parents' understanding of it. Therefore, exploring this understanding with each parent could contribute to the training process.

10.5.2 Maternal expectations of independence

The current findings provided information about the mothers' expectations of their children's development of functional skills. The mothers believed in pushing their children within their abilities to develop the mastery of skills that would increase their independence. These findings are in line with Lauruschkus et al. (2017), which found that the parents believed they had to motivate their children to participate in physical activities within their physical limits, which would help them to achieve independence.

Previous studies also provided some information about parents' expectations. In Mir and Tovey (2003) study, the mothers mentioned that they based their expectations of their children's status mainly based on their doctors' opinions. Similarly, Patel et al. (2017) found that the participants appeared to obtain information about their children from the professionals, and complained that they had low levels of knowledge about their children's potential to progress, which was frustrating. However, they also mentioned that they believed cerebral

palsy to be curable. In the current study it was not found that mothers linked their expectations with information imparted by the professionals.

In Gibson et al. (2012), the parents provided little information about their expectations for their children's improvement, however they did link the children's functional gains with the possibility of mastering walking skills. The mothers in this study also stated that they needed to be informed about how much training was sufficient, which indicated that they were unaware that their child's development would be limited. However, this study only investigated walking, a single aspect of child independence. In contrast, in Gannotti et al. (2001) study (2001), the parents of children with various different disabilities believed that disabled children were not expected to master any functional skills and were delicate, needed continual support, and were dependent. In the current study, while the mothers appeared to accept that gradual improvements would be made in order to achieve the optimal level of independence, they also realised that mastering skills would require time. Their acceptance was indicated in their avoidance of making early decisions and in their training schedule. Gibson et al. (2012) and Gannotti et al. (2001) findings clarified the parents' expectations of their children's progress. However, their beliefs were not explored in detail or linked to their children's development of independence. In contrast the current study provided some details regarding the mothers expectations, showing that while some mothers expected slow and gradual progress others believed in developmental ceiling limits, and other mothers believed in skills developing unexpectedly.

Furthermore, some mothers believed that a limit would be reached in their children's ability to develop independence. However, the study found that linking the child's gradual progress, the possibility of having a developmental ceiling, and the unexpected development of certain skills were in most cases linked with the mothers' religious beliefs. The interaction within the environmental level surrounding the mother can also be highlighted here, as the maternal beliefs regarding the expectations of their children are located in the first level of the environmental microsystem. These expectations in turn are influenced by the maternal religious and cultural beliefs that are located in the outermost level, the macrosystem.

When the mothers mentioned their acceptance of the gradual improvement in their children's independence, as Muslims and according to Islamic teachings, they were likely to emphasise their belief in the will of God. As mentioned earlier, they 'think positively of God', and they followed the scripture: '*I am as my slave expects me to be'* (Bukhari [7405]). One aspect of being a good Muslim is to expect the best from God. In some cases, in linking their acceptance of the developmental limitations of the child during the training process, the mothers might have decided that the child had reached his or her developmental ceiling earlier than the expected optimal level. This could be linked with the Islamic teaching of accepting what God wants, accepting God's gifts, and believing in *God's decree*, which is considered a major component of faith in Islam. Moreover, as explained in Section [10.3], the religious beliefs of Saudis are rooted in the

mother, and they influence other beliefs, even if she does not articulate them. Therefore, a mother's convictions about her child's potential to be independent cannot be separated from her religious beliefs

10.5.3 Motives to train

As explained in the findings chapter in Section [7.2.1.1], the mothers talked about their motives for training their children in certain areas. They linked training with the *child being a burden,* which could be reduced by training and with the goal of being able to *separate from the child* by reducing the need for supervision. Several studies that investigated the beliefs and experiences of parents of disabled children also recognised the feeling of 'burden' (Nazzal and AL-Rawajfah, 2017, Gannotti et al., 2001, Patel et al., 2017). Nazzal and AL-Rawajfah (2017) study (2017) on Jordanian mothers revealed that in raising their children, they bore the huge physical burden of the routine of self-care, as well as the financial burden of their children's requirements, which changed their family's priorities. In the current study, the mothers talked about the burden of caring for their children, but they linked the feeling of the burden with their plans to train the child to be independent.

Patel et al. (2017) study that investigated the health beliefs of caregivers in Botswana, however these participants mentioned more that one kind of burden. They talked about emotional, financial and physical burdens in raising their children with cerebral palsy. Because of the scarcity of wheelchairs, they had to carry their children everywhere, which led to back pain. In addition, there was a financial burden due to transportation, therapy and supply expenses, and they

were unable to work because of the child's demands (Patel et al., 2017). In the current study, although all of the children could use a wheelchair if needed, the mothers who talked about physical burden used to carry the children, even with a wheelchair present. Also, the mothers talked very little about any financial burden, perhaps because in Saudi Arabia, the health services include free rehabilitation sessions for children with disabilities. In addition, equipment, such as wheelchairs, is provided. Furthermore, parents of children with disabilities are provided a monthly subvention by the government.

In Gannotti et al. (2001), the findings indicated that mothers of disabled children believed that their children could not tolerate separation from them throughout their lives. These mothers also thought that disabled children were delicate and could die easily. However, taking care of these children and accepting the burden of a dependent child was part of these mothers' desire to appear strong. This finding was echoed in the current study, albeit limitedly, when one mother, M13, mentioned that she would carry her child to the toilet instead of supporting her as long as she was fit to do so, which might reflect some of the mothers' belief in accepting the burden of her child as part of her duty as a mother. Unlike Gannotti et al. (2001) findings (2001), many mothers in the current study believed that child separation was not optional especially because of gender segregation. However, in most cases, child burden and separation motivated the mother to train the child to develop independence, especially in self-care skills.

10.5.4 Training avoidance

In the current study, only a few mothers talked about occasions when they avoided training their children. Some mothers mentioned that they avoided training their children because they were afraid of harming them. Gibson et al. (2012) study was aimed at examining the beliefs of mothers of children with cerebral palsy regarding walking. The mothers mentioned that even though they worked at training their children they were not confident in their performance. For example, they were afraid of causing pain while training their children to walk. Similarly, in the current study, the mothers were afraid of harming their children, and this was reflected their lack of confidence in their training skills. In Gannotti et al. (2001), the mothers also avoided training because they felt that their children were fragile and easily harmed. In another study (Lauruschkus et al., 2017), which explored parents' experiences in participating in physical activity with their children with cerebral palsy, the findings showed that while the parents were also concerned about the child suffering pain and fatigue during physical activity, they did not mind continuing painful exercises. Moreover, although the parents believed that exercises were good, it was difficult to motivate their children to participate. This finding is in partial agreement with the current study, which found that some mothers avoided training their children because they refused to participate. Some of the mothers passed the responsibility for the painful walking training on to the father or the school's physical therapist to avoid dealing with the children's complaints of suffering. This reflects the mothers' beliefs regarding their

role in child training. Mentioning the mothers role, in Raman et al. (2010b), the mothers believed that they had little responsibility for training their children because they did not clearly understand their role in the rehabilitation process. In the current study, a few mothers talked about avoiding their children's training. Although avoidance seldom emerged in the current findings, it is worth emphasising because it provides some information about the importance that the mothers' placed on their roles in training their children to be independent.

10.5.5 Maternal beliefs of the father's role

Data from this study showed that the role played by the fathers of children with cerebral palsy were very varied. However, the main finding was the amount of weight the mothers placed on the presence or absence of the father during the training. Landry et al. (2015)findings (2015) were in line with the findings of the current study regarding the fathers' role. These findings showed disparity in the fathers' stances towards their children's disability, which ranged from being supportive, to providing little support, to being completely non-supportive. The mothers prioritised the fathers' support over external support, and their involvement enhanced the mothers' positive perceptions of her disabled child. Similarly, in the current study, the mothers valued the fathers' support, especially in the early stages of the child's disability.

In a study by Pelchat et al. (2009), 13 mothers and fathers described how they adapted to their children's disabilities. The findings showed

that the fathers felt more stigmatised and angry than the mothers did, and they immersed themselves in their work. Thus, they were slower to adapt than the mothers were. The fathers also found it difficult to focus on learning new things, while the mothers focused on the children's ability to communicate with people. In the current study, the fathers also seemed to be busy with work according to the mothers, but very few appeared to be stigmatised because of their children's disability. Mir and Tovey (2003) findings align with the current findings that the fathers were less involved in child care at home, and they were less aware of the physical and emotional stress caused by caring for a disabled child. However, these findings emerged from what authors found from interviewing the parents, not from the mothers' responses. Therefore, they might not reflect the mothers' perceptions.

In previous studies, the mothers did not generally provide details about the role that the mothers expected the fathers to have in training their children with cerebral palsy. However, in Landry et al. (2015), the mothers mentioned emotional support from the father. In the current study, most of the mothers talked about different aspects of the father's role. Some mothers' beliefs regarding the fathers' role were related to some cultural standards. The mothers expected more involvement from the father in preparing male children to transfer to the men's world according to the traditional norms of gender segregation. In addition, because public transportation was poor, and women were not allowed to drive, some mothers valued the father's contribution in transporting the child to seek medical advice or attend rehabilitation sessions.

10.5.6 Maternal beliefs about siblings' roles

The mothers acknowledged the participation of their disabled children's siblings. While they talked about the support they received in care and supervision, they also recognised the role the siblings played in motivating the disabled children in learning skills that helped to develop their independence. This issue was found also in the literature (Wippermann, 2013, Breslau et al., 1981). However, only a few studies examined the influence of siblings on developing the disabled child's independence skills, and there were no studies that explored the mothers' beliefs about the siblings' roles in the development of functional abilities in their disabled children. Freeborn and Knafl (2014) investigated the experience of eight women who had grown up as siblings of children with cerebral palsy. These women described their participation as mentors and friends when the child had few peers. They helped in guiding their siblings in developing mobility and self-care skills, and reading. This study provided information about the siblings' role in the training of children with cerebral palsy to develop independence.

In these studies, the siblings of disabled children were found to have been considered ready-made tutors. However, this relationship was risky because of the burden the sibling could feel and the possibility that it might inhibit their natural relations and playtime (Stoneman et al., 1988, Gibbs, 1998). In the current study, the mothers did not appear to be worried that the siblings might be burdened by helping to care for the disabled children. They mentioned that the siblings helped in

developing self-care skills, such as eating, grooming, dressing, and using the lavatory. The current findings showed that the mothers in this study believed that the siblings could act as role models to demonstrate the skills and motivate the disabled children to imitate them. This finding was supported by (James and Egel, 1986), who found that siblings learnt skills quickly and easily from each other. The current findings provided knowledge about the mothers' understanding of how their children might develop independence, and they reflected their beliefs about the roles of other family members in the training process.

The findings of the current study showed that the mothers' expectations and motivations regarding their children's development of independence were informed by their understanding of independence. This understanding influenced their decisions on whether to avoid or support their children in independence training. It also affected the mothers' acknowledgement of external support during the process of training their disabled children.

10.6 Limitations of the study

This study has some limitations. The mothers who took part in the study were self-selecting and because of the restrictions on transport for women and the view of qualitative studies they may represent a very distinct, progressive, sub-population of mothers. This led to the decision to use another study site and to extend the data collection period to give

more mothers the opportunity to participate. For the same reasons, seven mothers were not able to participate in the second round of interviews. Because of the conservative nature of Saudi culture, the mothers hesitated to participate and share information about their children and families. Moreover, qualitative research using interviews is not yet popular among people in Saudi society. Moreover, the findings showed that mothers valued the fathers' role and although the study was intended to explore the parental beliefs, it was not possible to interview the fathers because of the conservativeness of the society. Therefore the absence of the fathers' beliefs might be also a limitation in this study.

It was difficult to find a suitable service that would translate from vernacular Arabic to English, and as a result, because of the time required to complete the translation, the data collection period had to be extended. In addition, it was not possible to interview the fathers because of gender segregation in Saudi culture, where it is not generally culturally acceptable for a female interviewer to meet a male interviewee, or vice versa. Another limitation was that the transcripts were written using the vernacular Saudi accent, which was difficult to read and understand during data analysis. However, this difficulty was overcome by listening to the audio files while analysing the data.

10.7 Practical implications

A major goal of this study was to ensure that its findings would be applicable in clinical practice. For a rehabilitation program that focuses on developing the independence of children with cerebral palsy, and at the same time acknowledges the mothers' role during the child progression, understanding the mothers' beliefs regarding independence will add valuable knowledge that can be used when evaluating the child and planning new programmes. Furthermore, understanding the findings using socio-ecological systems provide conceptualization of the possible implications of the findings. As mentioned earlier, in the socio-ecological model the influence within the environmental level is bi-directional (Bronfenbrenner, 1977), but the focus in this study was on one direction, to examine how the mothers' surroundings relate with their beliefs. However, while identifying the implications of the findings the other direction can be highlighted, for instance, focusing on the influence of the mother's beliefs with her direct environment, for example the child, and the rehabilitation team. This will be explained further in the following section.

10.7.1 Implications for clinical practice

The beliefs that were obtained in this study were powerful and important, and might mark a turning point in acknowledging parental beliefs during the rehabilitation programmes of children with cerebral palsy. This shift could occur by involving the parents during the planning

of the child's rehabilitation programme, listening to them, explaining to them, and guiding them. The study highlighted the effects of the mothers' religious and cultural beliefs on their beliefs regarding their children's independence. Such beliefs should be considered in designing any educational programme for the mothers of disabled children. When they discuss a child's rehabilitation plan with the parents, the professionals should pay attention to the parents' expressions of their religious beliefs and consider them in motivating the parents during the child training process. Moreover, if the rehabilitation plans include the mothers, then their understanding and priorities concerning their children's independence must be acknowledged and discussed with them.

The mothers' training techniques are valuable. As described in the findings, one mother shared her storytelling technique with her child's schoolteachers and it was found to be beneficial. Rehabilitation teams would benefit by discussing the mothers' techniques and their children's preferred learning styles. Moreover, if the mothers were involved in the rehabilitation programme, it would be important to know their motives, anxieties and beliefs about their role in the rehabilitation process.

Some mothers stated that they tried to educate themselves about training. According to (Dambi et al., 2016), groups have been organised to educate cerebral palsy caregivers. Although such groups are not

popular in conservative Saudi society, it is suggested that groups of mothers of children with similar abilities and circumstances could be formed to share their experiences. These groups would also be valuable in educating the mothers and encouraging them, especially considering the research by (Smetana, 1994), that finds maternal beliefs might be influenced by other mothers' beliefs.

The children's self-motivation in accelerating their own training could be employed in the education programme for both mothers and children. The mothers could be taught how to motivate the child, and the part that the child plays in the training process could be clarified for them. Additionally, depending on the children's cognitive levels, they could be taught how to take responsibility in their training process.

10.7.2 Further research

Although the current study achieved its aims and succeeded in contributing to the corpus of knowledge of maternal beliefs about the independence of children with cerebral palsy, it also raised questions that should be addressed in further research on this area. The recommendations for further research include the following:

- Parental behaviour:

  Using the current study data, a future study could explore parental behaviours/attitudes about independence to determine

linkages and examine whether parents' beliefs influence their behaviour;

- Educational programme intervention:

  Using the data and the findings of the present study, an educational programme could be designed with the aims of encouraging the mothers' motivation to train their child to achieve independence and examining the children's levels of independence;

- A future study could be conducted to investigate progress towards the independence of children with cerebral palsy as well as parental beliefs regarding independence. The study could examine links between the children's performance and parental beliefs to understand the relationship between such beliefs and the children's outcomes;

- A further study that examines the siblings' role in child training to develop functional skills could be undertaken. The study also could investigate the siblings beliefs regarding their role.

10.8 Conclusion

This study found that beliefs about the independence of children with cerebral palsy among Saudi mothers could be identified by understanding their beliefs regarding the children's potential in training to be independent. These beliefs might be influenced by factors that relate to the mother, child, or external surroundings. However, the major findings were that these beliefs and factors were informed by the mothers' religious and cultural beliefs and that their religious beliefs were most likely to be the primary influence on other convictions.

Their religious beliefs were apparent when the mothers talked about the will and power of God to help their children develop, improve and achieve independence. Having deep religious beliefs and feeling a strong relationship with God led the mothers to trust God's justice in treating their children. Other factors were: expecting rewards from, and thinking positively about, God; training their children; being honest in taking responsibility for the child, and accepting the children's disability as God's gift. Other important factors were: avoiding negative thoughts, which were believed to come from the Devil, or being angry or dispirited, which might be considered a refusal of God's gift. The mothers reiterated all these beliefs when they talked about their children's potential and training to be independent.

Another major finding of the current study was that the mothers' understanding of independence varied and that prioritizing and expressing the concept of independence itself differed from one mother

to another. Knowledge of the mothers' understanding of independence guided us to consider their beliefs concerning their children's independence, which were found to reflect several mental, physical and personal factors. Identifying the mothers' expectations concerning the development of independence skills and their support for their children while practising these skills provided information about their beliefs regarding the children's ability to be independent.

Beliefs about their children's independence emerged from the mothers' motives and precautions during training and from exploring the creative techniques that reflected their ideas about how independence could be achieved. The mothers understood that other individuals shared the responsibility of training their children. They acknowledged the fathers' and siblings' roles in the training as well as the children's own responsibility in their development.

A major finding that arose from the current study is that the mothers beliefs regarding their children consisted of complex beliefs about their children's potential and training to be independent that were systemically interrelated with the mothers' religious and cultural beliefs to form maternal belief systems.

References

ABELSON, R. P. 1979. Differences Between Belief and Knowledge Systems*. *Cognitive science,* 3**,** 355-366.

AGARWAL, A. & VERMA, I. 2012. Cerebral palsy in children: An overview. *Journal of clinical orthopaedics and trauma,* 3**,** 77-81.

AHMAD, A. S. 1998. *Islam today: A short introduction to the Muslim world.* , IB Tauris.

AL SALLOUM, A. A., EL MOUZAN, M. I., AL OMAR, A. A., AL HERBISH, A. S. & QURASHI, M. M. 2011a. The prevalence of neurological disorders in Saudi children: a community-based study. *J Child Neurol,* 26**,** 21-4.

AL SALLOUM, A. A., EL MOUZAN, M. I., AL OMAR, A. A., AL HERBISH, A. S. & QURASHI, M. M. 2011b. The prevalence of neurological disorders in Saudi children: a community-based study. *Journal of child neurology,* 26**,** 21-24.

AL-AOUFI, H., AL-ZYOUD, N. & SHAHMINAN, N. 2012. Islam and the cultural conceptualisation of disability. *International Journal of Adolescence and Youth,* 17**,** 205-219.

AL-ASMARI, A., AL MOUTAERY, K., AKHDAR, F. & AL JADID, M. 2006. Cerebral palsy: incidence and clinical features in Saudi Arabia. *Disabil Rehabil,* 28**,** 1373-7.

AL-GHAMDI, Y., OME, R. M., KHALIL, M., ALI, S., BARMADA, R. & ABDELGADER, M. 2002. Clinical evaluation of disabled children in Al-Qassim region, Saudi Arabia. *Neurosciences (Riyadh),* 7**,** 272-7.

AL-HUSAYYIN, S. 2010. *Religious Freedom in Saudi Arabia,* Riyadh, Ghainaa Publications.

AL-SHAHRI, M. Z. 2002. Culturally Sensitive Caring for Saudi Patients. *Journal of Transcultural Nursing,* 13**,** 6.

AL-SULAIMAN, A. A. 1997. Neurological disorders in institutionalized patients in the Eastern Province of Saudi Arabia. *Saudi medical journal,* 18**,** 387-389.

AL-SULAIMAN, A. A., BADEMOSI, O. F., ISMAIL, H. M., AL-QULITI, K. W., AL-SHAMMARY, S. F., ABUMADINI, M. S., AL-UMRAN, K. U. & MAGBOOL, G. M. 2003. Cerebral palsy in Saudi children. *Neurosciences,* 8**,** 26-29.

ALBEJAIDI, F. M. 2010. Healthcare system in Saudi Arabia: An analysis of structure, total quality management and future challenges. *Journal of Alternative Perspectives in the Social Sciences,* 2**,** 794-818.

ALHARETH, Y. A., ALHARETH, Y. A. & DIGHRIR, I. A. 2015. Review of Women and Society in Saudi Arabia. *American Journal of Educational Research,,* 3**,** 5.

ALHUJAYLAN, H. A. 2014. *The Higher Education of Women in the Kingdom of Saudi Arabia: relationship of gender and academic performance in High School to the selection of college major among undergraduate students.* Master University of Akron.

ALJIBALY, M. 1998. *Sickness: Regulations and Exhortations (the Inevitable Journey - Part 1),* Arlington, Al-Kitaab & as-Sunnah Publishing.
ALKHUDAIR, R. & ALEISA, E. 2014. Applicability of the Pediatric Evaluation of Disability Inventory among Saudi children. *Disability Rehabilitation,* 36**,** 6.
ALMALKI, M., GERARD FITZGERALD, AND MICHELE CLARK. 2011. Health care system in Saudi Arabia: an overview/Aperçu du système de santé en Arabie saoudite. *Eastern Mediterranean health journal* 17.
ALMASABI, M. 2013. An overview of health system in Saudi Arabia. *Res J Med Sci,* 7**,** 70-4.
ALMUNAJJED, M. 1997. *Women in Saudi Arabia Today,* London, MACMILLAN PRESS LTD.
ALMUTAIR, A. S., PLUMMER, V., O'BRIEN, A. P. & CLEREHAN, R. R. 2014. Providing culturally congruent care for Saudi patients and their families. *Contemporary Nurse,* 46**,** 5.
ALVESSON, M. & SKÖLDBERG, K. 2010. *Reflexive Methodology: New Vistas for Qualitative Research*, Sage.
ANSARI, S. A. & AKHDAR, F. 1998. Prevalence of child disability in Saudi Arabia. *Disability and Rehabilitation,* 20**,** 25-8.
ATKINS, S. & MURPHY, K. 1993. Reflection: a review of the literature. *Journal of advanced nursing,* 18**,** 4.
AUNOLA, K., NURMI, J. E., NIEMI, P., LERKKANEN, M. K. & RASKU-PUTTONEN, H. 2002. Developmental dynamics of achievement strategies, reading performance, and parental beliefs. *Reading Research Quarterly,* 37**,** 310-327.
BAIRD, G., MCCONACHIE, H. & SCRUTTON, D. 2000. Parents' perceptions of disclosure of the diagnosis of cerebral palsy. *Archives of disease in childhood,* 83**,** 475-480.
BAKER, B. L., BLACHER, J. & OLSSON, M. B. 2005. Preschool children with and without developmental delay: behaviour problems, parents' optimism and well - being. *Journal of Intellectual Disability Research,* 49**,** 16.
BALF, C. & INGRAM, T. 1955. Problems in the classification of cerebral palsy in childhood. *British Medical Journal,* 2**,** 163.
BARRETT, R. & RANDLE, J. 2008. Hand hygiene practices: nursing students' perceptions. *Journal of Clinical Nursing,* 17**,** 1851-1857.
BAYLEY, N. 1993. *Bayley scales of infant development: Manual*, Psychological Corporation.
BEDELL, G. M., KHETANI, M. A., MARTHA A. COUSINS, COSTER, W. J. & LAW., M. C. 2011. Parent perspectives to inform development of measures of children's participation and environment. *Archives of Physical Medicine and Rehabilitation,* 92**,** 9.
BELLER, E. K. 1955. Dependency and independence in young children. *The Journal of genetic psychology,* 87**,** 25-35.

BENTON, T. & CRAIB, I. 2001. *Philosophy of Social Science: The Philosophical Foundations of Social Thought* Great Britain, PALGRAVE.
BERTERÖ, C. 2015. Developing qualitative methods - or "same old wine in a new bottle". *International Journal of Qualitative Studies on Health and Well-being*
BHASKAR, R. 1997. On the ontological status of ideas. *Journal for the Theory of Social Behaviour,* 27**,** 9.
BHASKAR, R. 2008. *A Realist Theory of*

Science, USA and Canada, Routledge.
BHATTY, I., MOTEN, A. A., TAWAKKUL, M. & AMER, M. 2009. Disability in Islam: Insights into theology, law, history, and practice. *Disabilities: Insights from across fields and around the world,* 1**,** 157-176.
BISMAN, J. 2010. Postpositivism and Accounting Research : A (Personal) Primer on Critical Realism

. *Australasian Accounting Business and Finance Journal,* 4**,** 22.
BLOMQUIST, K. B., BROWN, G., PEERSEN, A. & PRESLER, E. P. 1998. Transitioning to independence: challenges for young people with disabilities and their caregivers. *Orthopaedic Nursing,* 17**,** 27.
BLOOMBERG. 2014. *Bloomberg Rankings: Most effecient healthcare 2014: countries* [Online]. Available: Retrieved from http://www.bloomberg.com/rank [Accessed].
BOBATH, B. 1967. The very early treatment of cerebral palsy. *Developmental Medicine & Child Neurology,* 9**,** 373-390.
BORHEK, J. T. & CURTIS, R. F. 1983. *A sociology of belief,* Malbar. Florida, Robert E.Krieger Publishing Company.
BOTTOS, M., FELICIANGELI, A., SCIUTO, L., GERICKE, C. & VIANELLO, A. 2001. Functional status of adults with cerebral palsy and implications for treatment of children. *Developmental medicine and child neurology,* 43**,** 516-528.
BRAUN, V. & CLARKE, V. 2006. Using thematic analysis in psychology. *qualitatuve research in psychology,* 3**,** 24.
BRAUN, V. & CLARKE, V. 2013. *Successful Qualitative Research: A Practical Guide for Beginners,* London, Sage.
BRESLAU, N., WEITZMAN, M. & MESSENGER, K. 1981. Psychologic functioning of siblings of disabled children. *Pediatrics,* 67**,** 344-353.
BRONFENBRENNER, U. 1977. Toward an experimental ecology of human development. *American psychologist,* 32**,** 513.
BRONFENBRENNER, U. 1979. *The ecology of human development*, Harvard university press.
BUNNING, K., GONA, J. K., NEWTON, C. R. & HARTLEY., S. 2017. The perception of disability by community groups: Stories of local understanding, beliefs and challenges in a rural part of Kenya. *PloS one,* 12**,** e0182214.
BUTLER, A., HALL, H. & COPNELL, B. 2016. A guide to writing a qualitative systematic review protocol to enhance evidence -

based practice in nursing and health care. *Worldviews on Evidence-Based Nursing,* 13**,** 241-249.

CAELLI, K., RAY, L. & MILL, J. 2003. 'Clear as Mud': Toward Greater Clarity in Generic Qualitative Research. *International Journal of Qualitative Methods,* 2.

CANS, C. 2007. Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. *Developmental Medicine & Child Neurology,* 42**,** 816-824.

CARRUTH, B. R., ZIEGLER, P. J., GORDON, A. & HENDRICKS, K. 2004. Developmental milestones and self-feeding behaviors in infants and toddlers. *Journal of the American Dietetic Association,* 104**,** 51-56.

CARTER, S. & LITTLE, M. 2007. Justifying knowledge, justifying method, taking action: epistemologies, methodologies, and methods in qualitative research. *Qualitative health research,* 17**,** 12.

COLMAN, A. M. 2009. *A dictionary of psychology*, Oxford University Press.

COLMAN, A. M. 2015. *A dictionary of psychology*, Oxford University Press, USA.

COLVER, A. 2016. Outcomes for people with cerebral palsy: life expectancy and quality of life. *Paediatrics and Child Health,* 26**,** 383-386.

COLVER, A., FAIRHURST, C. & PHAROAH, P. O. D. 2014. Cerebral palsy. *The Lancet,* 383**,** 1240-1249.

CRABTREE, S. A. 2007a. Family responses to the social inclusion of children with developmental disabilities in the United Arab Emirates. *Disability & Society,* 22**,** 14.

CRABTREE, S. A. 2007b. Family responses to the social inclusion of children with developmental disabilities in the United Arab Emirates. *Disability & Society,* 22**,** 49-62.

CROOT, E., GRANT, G., COOPER, C. & MATHERS, N. 2008. Perceptions of the causes of childhood disability among Pakistani families living in the UK. *Health & Social Care in the Community,* 16**,** 606-613.

CROOT, E. J. 2012. The care needs of Pakistani families caring for disabled children: how relevant is cultural competence? *Physiotherapy,* 98**,** 351-356.

CROTTY, M. 1998. *The Foundations of Social Research: Meaning and Perspective in the Research Process,* Australia, SAGE Publications Ltd

.

CUNNINGHAM, M. M. & JILLINGS, C. 2006. Individuals' descriptions of living with fibromyalgia. *Clinical Nursing Research,* 15**,** 258-273.

DAMBI, J. M., MANDIZVIDZA, C., CHIWARIDZO, M., NHUNZVI, C. & TADYANEMHANDU, C. 2016. Does an educational workshop have an impact on caregivers' levels of knowledge about cerebral palsy? A comparative, descriptive cross-sectional

survey of Zimbabwean caregivers. *Malawi Medical Journal,* 28**,** 167-173.

DAMIGNANI, R., YOUNG, N., COLE, W., ANTHONY, A. & BADLEY, E. 2004. Impairment and activity limitation associated with epiphyseal dysplasia in children. *Archives of Physical Medicine and Rehabilitation,* 85**,** 1647-52.

DANERMARK, B., EKSTRÖM, M., JAKOBSEN, L. & KARLSSON, A. J. C. 2002. *Explaining Society: Critical realism in the social sciences,* Londen and New York, Routledge.

DE BILDT, A., SERRA, M., LUTEIJN, E., KRAIJER, D., SYTEMA, S. & MINDERAA, R. 2005. Social skills in children with intellectual disabilities with and without autism. *Journal of Intellectual Disability Research,* 49**,** 317-28.

DEGOTARDI, S., TORR, J. & CROSS, T. 2008. “He's got a mind of his own”: The development of a framework for determining mothers’ beliefs about their infants’ minds. *Early Childhood Research Quarterly,* 23**,** 259-271.

DOMÈNECH, D., MACIÀ, D. F. V. & SELVA, J. A. N. 2010. A systemic vision of belief systems and ideologies.

DONOVAN, J., VANLEIT, B., CROWE, T. & KEEFE, E. 2005. Occupational goals of mothers of children with disabilities: influence of temporal, social, and emotional contexts. *American Journal of Occupational Therapy,* 59**,** 249-61.

DOUMATO, E. A. & POSUSNEY, M. P. 2003. *Women and globalization in the Arab Middle East: gender, economy, and society*, Lynne Rienner Publishers.

EAMON, M. K. 2001. The effects of poverty on children's socioemotional development: An ecological systems analysis. *Social work,* 46**,** 256-266.

EDGLEY, A., STICKLEY, T., TIMMONS, S. & MEAL, A. 2016. Critical realist review: exploring the real, beyond the empirical. *Journal of Further and Higher Education,* 40**,** 14.

ENGLISH, D. J., KOUIDOU-GILES, S. & PLOCKE, M. 1994. Readiness for independence: A study of youth in foster care. *Children and Youth Services Review,* 16**,** 147-158.

EUNSON, P. 2012. Aetiology and epidemiology of cerebral palsy. *Paediatrics and Child Health,* 22**,** 361-366.

EZZI, S. W., TEAL, E. J. & IZZO, G. M. 2014. The influence of Islamic values on connected generation students in Saudi Arabia. *Journal of International Business and Cultural Studies Volume,* 9.

FINLAY, L. 2008. Reflecting on reflective practice. *PBPL paper,* 52**,** 27.

FINNIE, N. R. & BAVIN, J. 1997. *Handling the young child with cerebral palsy at home*, Butterworth-Heinemann.

FLETCHER, A. J. 2017. Applying critical realism in qualitative research: methodology meets method. *International Journal of Social Research Methodology* 20**,** 13.

FRANKENBURG, W. K. & DODDS, J. B. 1967. The Denver developmental screening test. *The Journal of pediatrics,* 71**,** 181-191.

FREEBORN, D. & KNAFL, K. 2014. Growing up with cerebral palsy: perceptions of the influence of family. *Child: care, health and development,* 40**,** 671-679.
FREEMAN, E. M. 1996. Welfare reforms and services for children and families: Setting a new practice, research, and policy agenda. *Social Work,* 41**,** 521-532.
GANNOTTI, M. E., HANDWERKER, W. P., GROCE, N. E. & CRUZ, C. 2001. Sociocultural influences on disability status in Puerto Rican children. *Physical Therapy,* 81**,** 1512-1523.
GARDNER, H. 2011. *Frames of mind: The theory of multiple intelligences*, Basic books.
GENERAL AUTHORITY FOR STATISTICS 2017. Total population statistics.
GETHING, L. 1985. Perceptions of disability of persons with cerebral palsy, their close relatives and able bodied persons. *Social Science & Medicine,* 20**,** 561-565.
GIBBS, G. 1998. *learning by doing: a guide to teaching and learning methods* FEU.
GIBSON, B., TEACHMAN, G., WRIGHT, V., FEHLINGS, D., YOUNG, N. & MCKEEVER, P. 2012. Children's and parents' beliefs regarding the value of walking: rehabilitation implications for children with cerebral palsy. *Child: care, health and development,* 38**,** 61-69.
GLASER, B. G. & STRAUSS, A. 1967. *The Discovery of Grounded Theory: Strategies for Qualitative Research.,* Chicago, IL, Aldine Publishing Co.
GOODNOW, J. J. 1988. Parents' ideas, actions, and feelings: Models and methods from developmental and social psychology. *Child development***,** 286-320.
GOODNOW, J. J. & COLLINS, W. A. 1990. *Development according to parents: The nature, sources, and sequences of parents' idea,* Hillsdale, NJ: Erlbaum.
GORMAN, M. M. 1993a. Hume's theory of belief. *Hume Studies,* 19**,** 89-101.
GORMAN, M. M. 1993b. Hume's Theory of Belief. *Hume Studies,* XIX**,** 89-102.
GRAHAM, H. K. 2005. Classifying cerebral palsy. *Journal of Pediatric Orthopaedics,* 25**,** 2.
GRAY, C. S., MILLER, D., KULUSKI, K. & COTT, C. 2014. Tying eHealth tools to patient needs: exploring the use of ehealth for community-dwelling patients with complex chronic disease and disability. *JMIR research protocols,* 3.
GRBICH, C. 1998. *Qualitative research in health: an introduction*, sage.
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.
GREENFIELD, P. M., FLORES, A., DAVIS, H. & SALIMKHAN, G. 2008. What happens when parents and nannies come from different cultures? Comparing the caregiving belief systems of nannies

and their employers. *Journal of Applied Developmental Psychology,* 29**,** 326-336.
GRIFFITHS, M. 1988. *Cerebral palsy: problems and practice*, Souvenir Press.
GUBA, E. G. & LINCOLN, Y. S. 1994. Competing paradigms in qualitative research. *Handbook of qualitative research* 163-194.
HAAK, P., LENSKI, M., HIDECKER, M. J. C., LI, M. & PANETH, N. 2009. Cerebral palsy and aging. *Developmental Medicine & Child Neurology,* 51**,** 16-23.
HACKER, P. M. S. 2004. 'Of the ontology of belief'. *in Mark Siebel and Mark Textor ed. Semantik und Ontologie.* Ontos Verlag, Frankfurt.
HALEY, S. M. 1992. *Pediatric evaluation of disability inventory (PEDI),* New England

, Medical Center Hospital, Incorporated, and PEDI Research Group.
HAMDAN, A. 2005. Women and education in Saudi Arabia: Challenges and achievements. *International Education Journal,* 6**,** 42-64.
HAMDAN, S. S. 1990. *Social change in the Saudi family.* DOCTOR OF PHILOSOPH Thesis, Iowa State University.
HANNA, S. E., ROSENBAUM, P. L., BARTLETT, D. J., PALISANO, R. J., WALTER, S. D., AVERY, L. & RUSSELL, D. J. 2009. Stability and decline in gross motor function among children and youth with cerebral palsy aged 2 to 21 years. *Developmental Medicine & Child Neurology,* 51**,** 295-302.
HANSEN, E. 2006. *Successful Qualitative Health Research,* USA, Open University Press.
HARKNESS, S. & SUPER, C. M. 1996. *Parents' Cultural Belief Systems: Their Origins, Expressions and Consequences,* New York, The Guilford Press.
HÄRKÖNEN, U. 2005. The Bronfenbrenner ecological systems theory of human development. *children,* 44**,** 45.
HEALTH STATISTICAL YEAR BOOK. 2017. Riyadh, Saudi Arabia: Ministry of Health. Available: https://www.moh.gov.sa/en/Ministry/Statistics/book/Documents/ANNUAL-STATISTICAL-BOOK-1438H.pdf [Accessed].
HEBERT, E. B. & KOULOUGLIOTI, C. 2010. Parental beliefs about cause and course of their child's autism and outcomes of their beliefs: A review of the literature. *Issues in comprehensive pediatric nursing,* 33**,** 149-163.
HINCHCLIFFE, A. 2007. *Children with cerebral palsy: a manual for therapists, parents and community workers*, Sage.
HINOJOSA, J. & ANDERSON, J. 1991a. Mothers' Perceptions of Home Treatment Programs for Their Preschool Children With Cerebral Palsy. *American Journal of Occupational Therapy,* 45**,** 273-279.
HINOJOSA, J. & ANDERSON, J. 1991b. Mothers' perceptions of home treatment programs for their preschool children with cerebral palsy. *American Journal of Occupational Therapy,* 45**,** 273-279.
HIRSJÄRVI, S. & PERÄLÄ-LITTUNEN, S. 2001. Parental beliefs and their role in child-rearing. *European Journal of Psychology of Education,* 16**,** 87-116.

HOLDEN, G. W. 1997. *Parents and the dynamics of child rearing*, Westview Press.
HSJC. 2018. *Joud Charitable Women Society* [Online]. Available: http://joud.org.sa/%D9%85%D8%B1%D9%83%D8%B2-%D8%AC%D9%88%D8%AF-%D9%84%D9%84%D8%B1%D8%B9%D8%A7%D9%8A%D8%A9-%D8%A7%D9%84%D9%86%D9%87%D8%A7%D8%B1%D9%8A%D8%A9-2/ [Accessed].
HUANG, Y. P., KELLETT, U. M. & ST JOHN, W. 2010. Cerebral palsy: experiences of mothers after learning their child's diagnosis. *Journal of advanced nursing,* 66**,** 1213-1221.
HUDSON, L. A. & OZANNE, J. L. 1988. Alternative Ways of Seeking Knowledge in Consumer Research. *Journal of Consumer Research,* 14**,** 508.
HUNT, M. 2009. Strengths and challenges in the use of interpretive description: reflections arising from a study of the moral experience of health professionals in humanitarian work. *Health Qualitative research,* 19**,** 8.
HUSSERL, E. 1970. *The Crisis of the European Sciences and Transcendental Phenomenology. ,* Evanston, IN, North University Press.
JACKSON, E. 2013. Choosing a methodology: Philosophical underpinning. *Practitioner Research in Higher Education* 7**,** 49-62.
JAMES, S. D. & EGEL, A. L. 1986. A direct prompting strategy for increasing reciprocal interactions between handicapped and nonhandicapped siblings. *Journal of Applied Behavior Analysis,* 19**,** 173-186.
JANSEN, L. M., KETELAAR, M. & VERMEER, A. 2003. Parental experience of participation in physical therapy for children with physical disabilities. *Developmental Medicine and Child Neurology,* 45**,** 58-69.
JANSSEN, I., FERRAO, T. & KING, N. 2016. Individual, family, and neighborhood correlates of independent mobility among 7 to 11-year-olds. *Preventive medicine reports,* 3**,** 98-102.
JOHNSTON, M. V. & HAGBERG, H. 2007. Sex and the pathogenesis of cerebral palsy. *Developmental Medicine & Child Neurology,* 49**,** 74-78.
KAHLKE, R. M. 2014. Generic Qualitative Approaches: Pitfalls and Benefits of Methodological Mixology. *International Journal of Qualitative Methods,* 13**,** 16.
KAI, J. 1996. "What worries parents when their preschool children are acutely ill, and why: a qualitative study". *Bmj* 313**,** 4.
KELLEGREW, D. H. 1998. Creating opportunities for occupation: An intervention to promote the self-care independence of young children with special needs. *American Journal of Occupational Therapy,* 52**,** 457-465.
KELLY, B. 2005. 'Chocolate - makes you autism': impairment, disability and childhood identities. *Disability and Society,* 20**,** 261-75.

KELLY, S. & BRESLIN, J. 2010. *Women's rights in the Middle East and North Africa: progress amid resistance*, Rowman & Littlefield Publishers.
KERREBROCK, N. & LEWIT, E. M. 1999. Children in self-care. *The Future of Children*, 151-160.
KIDDOO, D. A. 2012. Toilet training children: when to start and how to train. *Canadian Medical Association Journal,* 184, 511-511.
KING, G., ZWAIGENBAUM, L., KING, S., BAXTER, D., ROSENBAUM, P. & BATES, A. 2006. A qualitative investigation of changes in the belief systems of families of children with autism or Down syndrome. *Child: care, health and development,* 32, 353-369.
KING, N. & HORROCKS, C. 2010. *Interviews in Qualitative Research,* London, Sage.
KNOX, S. & BURKARD, A. 2009. Qualitative Research Interviews. *Psychotherapy Research,* 19, 9.
KNOX, V. 2008. Do parents of children with cerebral palsy express different concerns in relation to their child's type of cerebral palsy, age and level of disability? *Physiotherapy,* 94, 56-62.
KRIGGER, K. W. 2006. Cerebral palsy: an overview. *American family physician,* 73.
KRUIJSEN - TERPSTRA, A. J., KETELAAR, M., BOEIJE, H., JONGMANS, M. J., GORTER, J. W., VERHEIJDEN, J., LINDEMAN, E. & VERSCHUREN, O. 2014. Parents' experiences with physical and occupational therapy for their young child with cerebral palsy: a mixed studies review. *Child: care, health and development,* 40, 787-796.
KURDI, A. M., MESLEH, R. A., AL-HAKEEM, M. M., KHASHOGGI, T. Y. & KHALIFA, H. M. 2004. Multiple pregnancy and preterm labor. *Saudi medical journal,* 25, 632-637.
KUSSEROW, A. S. 1999. De-Homogenizing American Individualism: Socializing Hard and Soft Individualism in Manhattan and Queens. *Ethos,* 27, 210-234.
LANDRY, M. D., RAMAN, S. R., HARRIS, E., MADISON, L., PAREKH, M., BANKS, C., BHATTI, H. & WIJESINGHE, C. 2015. Exploring the factors that influence the perceptions of disability: a qualitative study of mothers of children with disabilities at a community-based rehabilitation centre in Sri Lanka. *WHO South-East Asia journal of public health* 4.
LAURUSCHKUS, K., NORDMARK, E. & HALLSTRÖM, I. 2017. Parents' experiences of participation in physical activities for children with cerebral palsy–protecting and pushing towards independence. *Disability and rehabilitation,* 39, 771-778.
LEATHAM, K. R. 2006. Viewing mathematics teachers' beliefs as sensible systems. *Journal of Mathematics Teacher Education,* 9, 91-102.
LEERKES, E. M., PARADE, S. H. & BURNEY, R. V. 2010. Origins of mothers' and fathers' beliefs about infant crying. *Journal of applied developmental psychology,* 31, 467-474.
LEVITT, S. 2013. *Treatment of cerebral palsy and motor delay*, John Wiley & Sons.

LIAMPUTTONG, P. 2007. *Childrearing and Infant Care Issues: A Cross-cultural Perspective*, Nova Publishers.
LINCOLN, Y. S., LYNHAM, S. A. & GUBA, E. G. 2011. *Paradigmatic controversies, contradictions, and emerging confluences, revisited*, The Sage handbook of qualitative research.
LUNA, J. 1989. Transcultural nursing care of Arab muslims. *Journal of Transcultural Nursing,* 1**,** 6.
MADI, S. 2014. *The voice of children with cerebral palsy (CP) and their mothers in Saudi Arabia.* University of Brighton.
MAJNEMER, A., SHEVELL, M., LAW, M., BIRNBAUM, R., CHILINGARYAN, G., ROSENBAUM, P. & POULIN, C. 2008. Participation and enjoyment of leisure activities in school-aged children with cerebral palsy. *Developmental Medicine & Child Neurology,* 50**,** 751-758.
MALINA, R. M. 2004. Motor development during infancy and early childhood: Overview and suggested directions for research. *International Journal of sport and health science,* 2**,** 17.
MALTERUD, K., SIERSMA, V. D. & GUASSORA, A. D. 2015. Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qualitative Health Research,* 26**,** 1753-1760.
MAROTZ, L. R. 2012. *Health, Safety, and Nutrition for the Young Child,* USA, Cengage Learning.
MARTEAU, T. M. & JOHNSTON, M. 1986. Determinants of beliefs about illness: a study of parents of children with diabetes, asthma, epilepsy, and no chronic illness. *Journal of psychosomatic research,* 30**,** 11.
MASON, J. 2002. *Qualitative Researching,* London, Sage.
MASON, M. 2010. Sample Size and Saturation in PhD Studies Using Qualitative Interviews

. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research,* 11.
MAXWELL, J. A. 2012. A Realist Approach for Qualitative Research: a realist stance for qualitative research. USA: SAGE Publications, Inc.
MAXWELL, J. A. & MITTAPALLI, K. 2007. The value of critical realism for qualitative research. *International Association for Critical Realism* 13.
MCCONACHIE, H., HUQ, S., MUNIR, S., AKHTER, N., FERDOUS, S. & KHAN, N. 2001. Difficulties for mothers in using an early intervention service for children with cerebral palsy in Bangladesh. *Child: care, health and development,* 27**,** 1-12.
MCGILLICUDDY-DE LISI, A. V. & SUBRAMANIAN, S. 1996. How do children develop knowledge. *In:* HARKNESS, S. & SUPER, C. M. (eds.) *Parents' cultural belief systems: Their origins, expressions, and consequences.* New York: The Guilford Press.
MERRIAM, S. B. 2009. *Qualitative Research: A Guide to Design and Implementation,* USA, Jossey-Bass.

MIGUEL, I., PIRES VALENTIM, J. & CARUGATI, F. 2010. Parental ideas and their role in childrearing: the idea-behavior connection. *Italian Journal of Sociology of Education,* 1.

MILBRATH, V. M., CECAGNO, D., SOARES, D. C., AMESTOY, S. C. & SIQUEIRA, H. C. H. D. 2008. Being a woman, mother to a child with cerebral palsy. *Acta Paulista de Enfermagem,* 21**,** 427-431.

MILES, M. B., HUBERMAN, A. M. & SALDAÑA, J. 2014. *Qualitative Data Analysis: A Methods Sourcebook,* USA, Sage.

MILLER, F., BACHRACH, S. J. & BACHRACH, S. J. 2006. *Cerebral palsy: A complete guide for caregiving,* Baltimore, Maryland, Johns Hopkins University Press.

MILLER, S. A. 1986. Parents' beliefs about their children's cognitive abilities. *Developmental Psychology,* 22**,** 276-284.

MILLER, S. A. 1988. Parents' beliefs about children's cognitive development. *Child development***,** 259-285.

MINCIU, I. 2011. CEREBRAL PALSY MANAGEMENT. *Therapeutics, Pharmacology & Clinical Toxicology,* 15.

MINGERS, J. 2006. *Realising Systems Thinking: Knowledge and Action in Management Science,* USA, Springer.

MINISTRY OF ECONOMY AND PLANING. 2010. *Ninth development plan 2010-2014* [Online]. Riyadh. Available: https://www.mep.gov.sa/en/AdditionalDocuments/PlansEN/9th/Ninth Development Plan - Chapter 4 - National Economy Under The Ninth Development Plan .pdf [Accessed].

MINISTRY OF LABOR AND SOCIAL DEVELOPMENT. 2017. *Persons with disabilities* [Online]. Available: https://mlsd.gov.sa/ar/services/620 [Accessed].

MIR, G. & TOVEY, P. 2003. Asian carers' experiences of medical and social care: the case of cerebral palsy. *British Journal of Social Work,* 33**,** 465-479.

MORGAN, F. & TAN, B.-K. 2011a. Parental views from rural Cambodia on disability causation and change. *Disability and rehabilitation,* 33**,** 2114-2120.

MORGAN, F. & TAN, B. K. 2011b. Rehabilitation for children with cerebral palsy in rural Cambodia: parental perceptions of family-centred practices. *Child: care, health and development,* 37**,** 7.

MORROW, A., HAYEN, S. Q., SCHEINBERG, A. & CRAIG, J. C. 2012. A comparison of doctors', parents' and children's reports of health states and health-related quality of life in children with chronic conditions. *Child: care, health and development,* 38**,** 10.

MORSE, J. M. 1994. Emerging from the data: Cognitive processes of analysis in qualitative inquiry. *Critical issues in qualitative research.* Menlo Park, CA: Sage.

MSALL, M. E., DIGAUDIO, K., ROGERS, B. T., LAFOREST, S., CATANZARO, N. L., CAMPBELL, J., WILCZENSKI, F. & DUFFY, L. C. 1994. The Functional Independence Measure for Children (WeeFIM)

Conceptual Basis and Pilot Use in Children With Developmental Disabilities. 33**,** 10.

MURPHEY, D. 1992. Constructing the child: Relations between parents' beliefs and child outcomes*1. *Developmental Review,* 12**,** 199-232.
MUTCH, L., ALBERMAN, E., HAGBERG, B., KODAMA, K. & PERAT, M. V. 1992. Cerebral palsy epidemiology: where are we now and where are we going? *Developmental Medicine & Child Neurology,* 34**,** 547-551.
NATIONAL GUIDELINE ALLIANCE UK. 2017. *Cerebral Palsy in Under 25s: Assessment and Management* [Online]. [Accessed].
NAZZAL, M. S. & AL-RAWAJFAH, O. M. 2017. Lived experiences of Jordanian mothers caring for a child with disability. *Disability and rehabilitation***,** 11.
NELSON, D. L. 1996. Therapeutic occupation: A definition. *American Journal of Occupational Therapy,* 50**,** 775-782.
NESPOR, J. 1987. The role of beliefs in the practice of teaching. *Journal of curriculum studies,* 19**,** 317-328.
NEVO, J. 1998. Religion and national identity in Saudi Arabia. *Middle Eastern Studies,* 34**,** 20.
OCHSENWALD, W. 1981. Saudi Arabia and the Islamic revival. *International Journal of Middle East Studies* 13**,** 16.
OLSEN, N. R., BRADLEY, P., LOMBORG, K. & NORTVEDT, M. W. 2013. Evidence based practice in clinical physiotherapy education: a qualitative interpretive description

. *BMC medical education* 13**,** 52.
OMAIR, F. A. A. 2005. Despair and hope and their impact on the revival of Islamic life. *Journal of Sharia and Islamic Studies*.
ONWUEGBUZIE, A. J. & LEECH, N. L. 2007. A Call for Qualitative Power Analyses. *Quality & Quantity,* 41**,** 105-121.
ØSTENSJØ, S. & BROGREN, E. 2003. Everyday functioning in young children with cerebral palsy: functional skills, caregiver assistance, and modifications of the environment. *Developmental Medicine & Child Neurology,* 45**,** 603-612.
ÖSTERHOLM, M. Beliefs: A theoretically unnecessary construct? Proceedings of the Sixth Congress of the European Society for Research in Mathematics Education. January 28th-February 1st 2009, Lyon, France, 2010. Institut National de Recherche Pédagogique, 154-163.
PAJARES, M. F. 1992. Teachers' beliefs and educational research: Cleaning up a messy construct. *Review of educational research,* 62**,** 307-332.
PATEL, P., BAIER, J., BARANOV, E., KHURANA, E., GAMBRAH-SAMPANEY, C., JOHNSON, A., MONOKWANE, B. & BEARDEN, D. 2017. Health beliefs regarding pediatric cerebral palsy among caregivers in Botswana: A qualitative study. *Child: care, health and development,* 43**,** 861-868.
PATTON, M. Q. 2002. *Qualitative Research & Evaluation Methods,* USA, Sage.
PEHKONEN, E. & PIETILÄ, A. On relationships between beliefs and knowledge in mathematics education. Proceedings of the

CERME-3 (Bellaria) meeting. http://www. dm. unipi. it/~ didattica/CERME3/draft/proceedings_draft/TG2_draft, 2003.
PELCHAT, D., LEVERT, M.-J. & BOURGEOIS-GUÉRIN, V. 2009. How do mothers and fathers who have a child with a disability describe their adaptation/transformation process? *Journal of Child Health Care,* 13**,** 239-259.
PLUYE, P. 2011. Collaborative development of a mixed methods appraisal tool: A public WIKI workspace.
PLUYE, P., GAGNON, M.-P., GRIFFITHS, F. & JOHNSON-LAFLEUR, J. 2009. A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in mixed studies reviews. *International journal of nursing studies,* 46**,** 529-546.
POPE, C. & MAYS, N. 2002. *Qualitative Research in Health Care,* UK, Blackwell publishing Ltd.
PSRC. 2010. *Prince Sultan Rehabilitation Centre* [Online]. Available: http://www.psrc.org.sa/index_Eng.aspx [Accessed].
RAEFF, C. 2000. European-American parents' ideas about their toddlers' independence and interdependence. *Journal of Applied Developmental Psychology,* 21**,** 183-205.
RAIKES, A. 2017. Measuring child development and learning. *European Journal of Education,* 52**,** 511-522.
RAMAN, S. R., MANDODA, S., HUSSAIN, L. K., FOLEY, N., HAMDAN, E. & LANDRY, M. 2010a. Exploring the meaning of childhood disability: perceptions of disability among mothers of children with disabilities (CWD) in Kuwait. *World health & population,* 11**,** 49-60.
RAMAN, S. R., MANDODA, S., HUSSAIN, L. K., FOLEY, N., HAMDAN, E. & LANDRY, M. 2010b. Exploring the meaning of childhood disability: perceptions of disability among mothers of children with disabilities (CWD) in Kuwait. *World health & population,* 11.
RASSOOL, G. H. 2000. The crescent and Islam: healing, nursing and the spiritual dimension. Some considerations towards an understanding of the Islamic perspectives on caring. *Journal of advanced nursing,* 32**,** 9.
RAYA, A. F., RUIZ-OLIVARES, R., PINO, J. & HERRUZO, J. 2013. Parenting style and parenting practices in disabled children and its relationship with academic competence and behaviour problems. *Procedia-Social and Behavioral Sciences,* 89**,** 702-709.
RENTINCK, I., KETELAAR, M., SCHUENGEL, C., STOLK, J., LINDEMAN, E., JONGMANS, M. & GORTER, J. 2010. Short-term changes in parents' resolution regarding their young child's diagnosis of cerebral palsy. *Child: care, health and development,* 36**,** 703-708.
RODRIGUEZ, B. L. & OLSWANG, L. B. 2003. Mexican-American and Anglo-American mothers' beliefs and values about child rearing, education, and language impairment. *American Journal of Speech-Language Pathology,* 12**,** 452-462.

ROKEACH, M. 1968. Beliefs, attitudes and values: A theory of organization and change.
RONDERO, H. V., SELBER, K., TIJERINA, M. & MALLOW, J. 2005. Reaching Out: Evaluation of a Health Promotion Website for Children with Disabilities and Their Families. *Journal of Social Work in Disability and Rehabilitation,* 4**,** 87-103.
ROSENBAUM, P. 2003a. Cerebral palsy: what parents and doctors want to know. *BMJ: British Medical Journal,* 326**,** 970.
ROSENBAUM, P. 2003b. Cerebral palsy: what parents and doctors want to know. . *British Medical Journal,* 326**,** 5.
ROSENBAUM, P., PANETH, N., LEVITON, A., GOLDSTEIN, M., BAX, M., DAMIANO, D., DAN, B. & JACOBSSON, B. 2007a. A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol Suppl,* 109**,** 8-14.
ROSENBAUM, P., PANETH, N., LEVITON, A., GOLDSTEIN, M., BAX, M., DAMIANO, D., DAN, B. & JACOBSSON, B. A. 2007b. A report: the definition and classification of cerebral palsy April 2006. *Developmental Medicine & Child Neurology,* 49**,** 8-14.
ROSKAM, I. 2005. A comparative study of mothers' beliefs and childrearing behaviour: The effect of the child's disability and the mother's educational level. *European journal of psychology of education,* 20**,** 139-153.
RUSSELL, F. 2003. The expectations of parents of disabled children. *British Journal of Special Education,* 30**,** 144-149.
SANDELOWSKI, M. & BARROSO, J. 2003. Classifying the Findings in Qualitative Studies. *Qualitative Health Research,* 13**,** 905-923.
SAUL, R. & PHILLIPS, D. 1999. Ghosts and germs: Cerebral Palsy in Nepal: A preliminary exploration of cosmology and disability. *Disability and development: Learning from action and research on disability in the majority world***,** 210-227.
SAUNDERS, M. N. K., THORNHILL, A. & LEWIS, P. 2009. *Research Methods for Business Students,* England, Pearson.
SAVAGE, J. S., HAISFIELD, L., FISHER, J. O., MARINI, M. & BIRCH, L. L. 2012. Do children eat less at meals when allowed to serve themselves? *The American journal of clinical nutrition,* 96**,** 36-43.
SEN, E. & YURTSEVER, S. 2007. Difficulties experienced by families with disabled children. *Journal for Specialists in Pediatric Nursing,* 12**,** 238-252.
SENESE, V. P., BORNSTEIN, M. H., HAYNES, O. M., ROSSI, G. & VENUTI, P. 2012. A cross-cultural comparison of mothers' beliefs about their parenting very young children. *Infant Behavior and Development,* 35**,** 10.
SHAUNAK, M. & KELLY, V. B. 2017. Cerebral palsy in under 25 s: assessment and management (NICE Guideline NG62). *Archives of Disease in Childhood-Education and Practice***,** edpract-2017-312970.
SIGEL, I. 1985. *Parental belief systems: the psychological consequences for children,* Hillsdale, NJ:Erlbaum.

SIGEL, I., ANN V. MCGILLICUDDY-DE LISI & GOODNOW, J. J. 1992. *Parental belief systems: the psychological consequences for children,* New york, Psychology Press (Tylor& Francis Group).
SILVERMAN, D. 2011. *Qualitative Research*, Sage.
SINGHI, P. D. 2004. Cerebral palsy-management. *The Indian Journal of Pediatrics,* 71**,** 635-639.
SKINNER, D., RODRIGUEZ, P. & JR, D. B. B. 1999. Qualitative analysis of Latino parents' religious interpretations of their child's disability. *Journal of Early Intervention* 22**,** 15.
SMETANA, J. G. 1994. *Beliefs about parenting: Origins and developmental implications*, Jossey-Bass.
SMITH, A. 2001. Perception and belief. *Philosophy and Phenomenological Research,* 62**,** 283-309.
SMITS, D.-W., KETELAAR, M., GORTER, J. W., VAN SCHIE, P., DALLMEIJER, A., JONGMANS, M. & LINDEMAN, E. 2011. Development of daily activities in school-age children with cerebral palsy. *Research in developmental disabilities,* 32**,** 222-234.
STANTON, M. 2002. *The cerebral palsy handbook: A practical guide for parents and carers*, Vermilion.
STIVER, I. P. 1984. *The meanings of" dependency" in female-male relationships*, Stone Center for Developmental Services and Studies, Wellesley College Wellesley, Mass.
STOKOLS, D. 1996. Translating social ecological theory into guidelines for community health promotion. *American journal of health promotion* 10**,** 17.
STONEMAN, Z., BRODY, G. H., DAVIS, C. H. & CRAPPS, J. M. 1988. Childcare responsibilities, peer relations, and sibling conflict: Older siblings of mentally retarded children. *American Journal on Mental Retardation*.
SUIZZO, M.-A. 2002. French parents' cultural models and childrearing beliefs. *International Journal of Behavioral Development,* 26**,** 297-307.
SUIZZO, M.-A. 2007. Parents' goals and values for children: Dimensions of independence and interdependence across four US ethnic groups. *Journal of Cross-Cultural Psychology,* 38**,** 506-530.
SYKES, W. R. 1989. Belief systems in administration and training. *J Relig Health,* 28**,** 97-108.
TAHA, S. & MAHDI, A. 1984. Cerebral palsy in Saudi Arabia: a clinical study of 102 cases. *Annals of tropical paediatrics,* 4**,** 155-158.
TATLA, S. K., SAUVE, K., VIRJI-BABUL, N., HOLSTI, L., BUTLER, C. & LOOS, H. F. M. 2013. Evidence for outcomes of motivational rehabilitation interventions for children and adolescents with cerebral palsy: an American Academy for Cerebral Palsy and Developmental Medicine systematic review. *Developmental Medicine & Child Neurology,* 55**,** 593-601.
TAUNT, H. M. & HASTINGS, R. P. 2002. Positive impact of children with developmental disabilities on their families: A preliminary

study. *Education and Training in Mental Retardation and Developmental Disabilities*, 410-420.
TAYLOR, M. C. 2001. Independence and empowerment: Evidence from the student perspective. *British Journal of Occupational Therapy,* 64, 245-252.
TEACHMAN, G. & GIBSON, B. E. 2013. Children and youth with disabilities: Innovative methods for single qualitative interviews. *Qualitative health research,* 23, 264-274.
TECKLIN, J. S. 2008. *Pediatric physical therapy*, Lippincott Williams & Wilkins.
THE WORLD FACTBOOK. 2017. *Background of Saudi Arabia* [Online]. The Central Intelligence Agency. Available: https://www.cia.gov/library/publications/the-world-factbook/geos/sa.html [Accessed].
THORNE, S. 2016. *Interpretive Description: Qualitative Research for Applied Practice* New York, Routledge.
THORNE, S., CON, A., MCGUINNESS, L., MCPHERSON, G. & HARRIS, S. R. 2004a. Health Care Communication Issues in Multiple Sclerosis: An Interpretive Description. *Qualitative Health Research,* 14, 18.
THORNE, S., CON, A., MCGUINNESS, L., MCPHERSON, G. & HARRIS, S. R. 2004b. Health care communication issues in multiple sclerosis: an interpretive description. *Qualitative health research,* 14, 5-22.
THORNE, S., KIRKHAM, S. R. & O"FLYNN-MAGEE, K. 2004c. The Analytic Challenge in Interpretive Description. *International Journal of Qualitative Methods,* 3, P 1.
THORNE, S. E. 1991. Methodological Orthodoxy in Qualitative Nursing Research: Analysis of the Issues. *Qualitative health research,* 1, 21.
TOSI, L. L., MAHER, N., MOORE, D. W., GOLDSTEIN, M. & AISEN, M. L. 2009. Adults with cerebral palsy: a workshop to define the challenges of treating and preventing secondary musculoskeletal and neuromuscular complications in this rapidly growing population. *Developmental Medicine & Child Neurology,* 51, 2-11.
TRACY, S. J. 2010. Qualitative Quality: Eight "Big-Tent" Criteria for Excellent Qualitative Research. *Qualitative Inquiry,* 16, 14.
TURFE, T. A. 1996. *Patience in Islam: Sabr*, TTQ, INC.
TURNBULL, A. P. & TURNBULL III, H. R. 1985. Developing independence. *Journal of Adolescent Health Care,* 6, 108-119.
VASSILIEV, A. 2013. *The History of Saudi Arabia.*, Saqi.
VEITCH, J., BAGLEY, S., BALL, K. & SALMON, J. 2006. Where do children usually play? A qualitative study of parents' perceptions of influences on children's active free-play. *Health & place,* 12, 383-393.
WALSH, D. & EVANS, K. 2014. Critical realism: An important theoretical perspective for midwifery research. *Midwifery,* 30, e1-e6.

WHITTINGHAM, K., WEE, D., SANDERS, M. R. & BOYD, R. 2013. Sorrow, coping and resiliency: parents of children with cerebral palsy share their experiences. *Disability and rehabilitation,* 35**,** 1447-1452.

WIART, L., RAY, L., DARRAH, J. & MAGILL-EVANS, J. 2010. Parents' perspectives on occupational therapy and physical therapy goals for children with cerebral palsy. *Disability and rehabilitation,* 32**,** 248-258.

WIPPERMANN, J. A. 2013. The Quality of Life of Families of Children with Cerebral Palsy.

WOLCOTT, H. F. 1999. *Ethnography: a way of seeing,* Walnut Creek,CA, AltaMira Press.

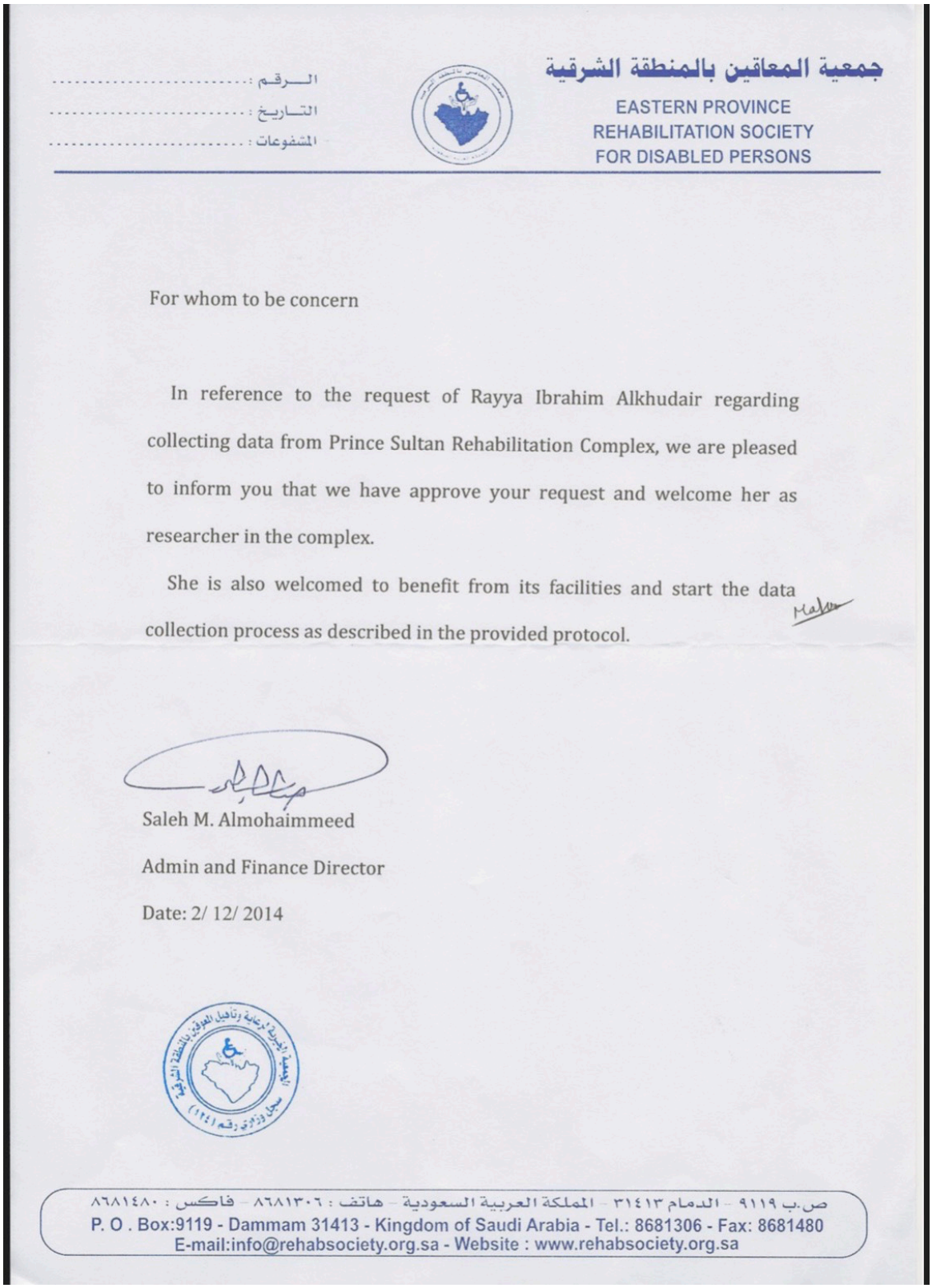
WORLD HEALTH ORGANIZATION. 2000. *The world health report 2000: health systems: improving performance* [Online]. World Health Organization. [Accessed].

YEH, M., HOUGH, R. L., MCCABE, K., LAU, A. & GARLAND, A. 2004. Parental beliefs about the causes of child problems: Exploring racial/ethnic patterns. *Journal of the American Academy of Child & Adolescent Psychiatry,* 43**,** 605-612.

ZVARA, B. J., SCHOPPE‐SULLIVAN, S. J. & DUSH, C. K. 2013. Fathers' involvement in child health care: associations with prenatal involvement, parents' beliefs, and maternal gatekeeping. *Family relations,* 62**,** 649-661.

Appendices

Appendix 1: Ethical approval from PSRC



جمعية المعاقين بالمنطقة الشرقية

EASTERN PROVINCE
REHABILITATION SOCIETY
FOR DISABLED PERSONS

الـــرقـم : .....
التـــاريـخ : .....
المشفوعات : .....

For whom to be concern

In reference to the request of Rayya Ibrahim Alkhudair regarding collecting data from Prince Sultan Rehabilitation Complex, we are pleased to inform you that we have approve your request and welcome her as researcher in the complex.

She is also welcomed to benefit from its facilities and start the data collection process as described in the provided protocol.

Saleh M. Almohaimmeed

Admin and Finance Director

Date: 2/ 12/ 2014

ص.ب ٩١١٩ - الدمام ٣١٤١٣ - المملكة العربية السعودية - هاتف : ٨٦٨١٣٠٦ - فاكس : ٨٦٨١٤٨٠
P. O . Box:9119 - Dammam 31413 - Kingdom of Saudi Arabia - Tel.: 8681306 - Fax: 8681480
E-mail:info@rehabsociety.org.sa - Website : www.rehabsociety.org.sa

Appendix 2: Participants information sheet

Study title: Parental belief systems regard independence of children with cerebral palsy among Saudi mothers.

Name of the researcher: Mrs. Rayya Ibrahim Alkhudair, Dr Joanne Lymn, Dr Pippa Hemingway and Dr Claire Diver.

We would like to invite you to take part in the present study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Please take your time read the following information carefully and discuss it with others if you wish. Take your time also to consider wither or not you wish to take part. Please feel free to contact me and ask about anything that is not clear or if you would like more information.

What is the purpose of the study?

Main purpose is to identify parental belief systems regard independence in functional activities including self-care and mobility of children with mild and moderate cerebral palsy among Saudi parents.

Why have I been invited?

You are invited to participate in this study because you are a parent of child with mild or moderate cerebral palsy. We are also inviting 9 participants like you to take part.

Do I have to take part?

It is entirely up to you weather or not to take part. If you decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. You are also free to change your mind and withdraw at any time without giving a reason. Your decisions not to take part will not in any way affect the standard of service you receive.

What will happen to me if I take part?

If you are interested in taking part of the study, I will invite you to an interview. The interview time and place will be arranged between us a head of time. The interview duration is between one and two hours. It will be tape-recorded.

Expenses and payment

Participant will not be paid (an inconvenience allowance) to participate in the study.

What is the possible disadvantages and risks of taking part?

There is no disadvantage or risk involved of taking part

What are possible benefits of taking part?

We cannot promise that the study will help you immediately, but the information we get from the study may help to improve the child with cerebral palsy outcome after rehabilitation program.

What if there is a problem?

If you have concern about any aspect of this study, you can speak to the researchers or me. We will do our best to answer your questions. Our contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting (PSRC) complains. Details can be obtained from the complex administration.

Will my taking part in the study be kept confidential?

Yes, all information which will be collected during the course of the research, will be kept on a password-protected computer and notes are security locked up. Information about you that leaves the research domain will not bear your name or address, so you cannot be traced or recognized from it.

What will happen if I don't want to carry on with the study?

Your study participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis.

What will happen to the results of the research study?

The research is being carried out as part of the requirements of the PhD for Mrs. Rayya Alkhudair at the University of Nottingham. It is planed that the results of this study will be published in the subject relevant peer reviewed research journals in the last phase or after completion of the research.

Who is organizing and funding the research?

This research is being organized by the University of Nottingham, and is being funded by the Ministry of High Education in Saudi Arabia.

Who has reviewed the study?

This study has been reviewed and approved by the research Ethical Committee in (PSRC). This study has been reviewed and given favorable opinion by University of Nottingham, Medical School Research Ethics Committee.

Further information and contact details:

- Mr. Rayya Alkhudair
  PhD (Health Studies) Student

  School of Health Sciences

  Faculty of Medicine & Health Sciences

  University of Nottingham

  B Floor (South Block)

  Queen's Medical Centre

Nottingham, NG7 2HA

Telephone: +966541243582

E-mail: mxra5@nottingham.ac.uk

- Dr. Joanne Lymn
Director of Research/ PhD Programme Director

School of Health Sciences

Faculty of Medicine and Health Sciences

University of Nottingham

Queen's Medical Centre

Nottingham

NG7 2UH

Telephone: +44 (0115) 82 30805

Fax: +44 (0115) 82 31208

E-mail: joanne.lymn@nottingham.ac.uk

- Dr. Pippa Hemingway
Lecturer in Nursing Children and Young People
School of Health Sciences

Faculty of Medicine and Health Sciences

University of Nottingham

Queen's Medical Centre

Room B43

Nottingham

NG7 2UH

Telephone: +44 (0115) 82 30898

Fax: +44 (0115) 82 30999

E-mail: pippa.hemingway@nottingham.ac.uk

- Dr. Claire Diver
  Lecturer
  School of Health Sciences
  Faculty of Medicine and Health Sciences
  University of Nottingham
  Nottingham City Hospital
  Room B89 Clinical Sciences
  Hucknall Road
  Nottingham
  NG5 1PB
  Telephone: +44 (0115) 82 31786
  E-mail: Claire.diver@nottingham.ac.uk

Appendix 3: Consent form

Title of the Study: Parental belief systems regard independence of children with cerebral palsy among Saudi mothers.

Name of the researcher(s): Mrs. Rayya Alkhudair, Dr. Joanne Lymn, Dr. Pippa Hemingway, Dr. Claire Diver

Name of the participant:	**Please initial box**
1. I confirm that I have read and understand the information sheet, dated ……. for the above study and have had the opportunity to ask questions.	☐
2. I understand my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis.	☐
3. I understand that relevant sections of my medical notes and data collected in the study may be looked at by authorized individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential.	☐
4. I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports.	☐
5. I agree to take part in the above study	☐

Name of the participant	Date	Signature
Name of person taking consent	Date	Signature

Appendix 4: Interview guide (first round)

The interview will start with appreciation for the acceptance to join the study, and reminding of the mothers' right to withdraw at any time from the study. Then announcing that tape recording will start. Greeting with 'personal information and background', and explaining what do I mean by the word 'belief' to avoid misunderstanding. Then start 'research questions', estimating interview duration is approximate 90 mints and should not exceed 120 mints.

Proposed questions:

- Ask about child health history, how did she know about the disability, expand if she talk about her feeling when she first know.
- Ask about child current physical abilities
- Ask about father role and beliefs
- Compare between child abilities at home and school
- Understanding of child rights and what she think about it
- Ask about relation between safety and independence, speech and independence.
- Mother role in developing independence, fitting child training in her schedule.
- Ask about relation between understanding and independence.
- Ask about surrounding people influence and outside society
- Ask about relation between social abilities and independence
- Relation between child performance and mother encourage
- If mother talk about link between her and her child feelings and/or abilities ask her to expand
- If she showed optimist or pessimist, ask her what is behind this and ask to expand

Appendix 5: Second Round Interview Guide

Primary questions:

Q: How do you see that child improvement affects your child's mental health positively? And visa versa? Do you think that his/her mental health might become a motive for you or him to improve? To what extent and how? Explain to me.

Do you think that promoting the child will improve his psychology and then will improve his independence? How?

Q: Do you believe that his brothers and sisters encourage his independence? How: by copying? Or by the desire to compete and play? Is this a thing you observed recently or a long time ago? How to you utilize it?

Q: Do you think you know the real abilities of your child? How this is helping you to encourage his/her independence? If not what makes you confused? Explain to me.

Q: Do you feel that your child carries some of the responsibility regarding his/her independence in some areas? How? And how you are dealing with this?

Q: Do you spend private time with (…….)? Why? Do you think this affects his/her improvement in independence? (She said yes or no).

Q: You told me before that his/her interaction is more with younger children? How do you link this with his/her independence level? To what extent may this affect you? Talk about this more please.

Q: What is the most significant thing that currently makes you feel optimistic about your child's improvement? How does his/her improvement affect your motives? Make you work more or less?

Q: Talk to me about your strategy in training your child, do you train him/her all at the same time (dressing, toileting, etc.) or step by step, does his/her slowness in acquiring any skill affect your motives in the other skills or do you try not to link them? Talk to me about your thoughts here.

Q: How do you feel when your child tries to be more independent? Socially or physically? What do you do and why?

Q: As a religious society, how do you link working hard at improving your child and your faith and acceptance of God's gift? Is there anything in this regard from your surroundings? Talk to me how you receive this and think about it?

Q: How do link your hard work on child training and faith (relying on God)? Talk to me about your belief in this.

Q: Did the issue of (*najasah*) delay your child's toilet training? (*Najasah* if some of the child urine or bowel movements will affect the mother's cleanliness for prayer).

Secondary questions:

Q: Do you feel that improving the independence of (….) will significantly reduce some of the burden and responsibilities on you? Do you find this a motive sometimes?

Q: Along with your child's growth do you sometimes do something in the house structure or organization that facilitates independence? When? to what extent do you find this helps with independence?

Q: If you find yourself confused sometimes and unable to understand something regarding (….) skills, from where do you seek advice?

Q: How do you define your role as parents in encouraging your child's independence? How much do you believe you can do? If not much, how can you do it, and why?

Q: When we talk about a child's independence what do you expect from him/her? What are the most important things?

Q: How do you think the mother-child special attachment affects your child's independence?

Q: Do you find the child's interaction with peers or doing outdoor activities improves his/her independence? Why? To what extent? Explain please.

Q: Within your child's growing stage, how do you find your consultation of the professionals (rehabilitation team) helpful? Do you believe the

information from the consultation helped you in improving your child's independence? Do you usually seek their opinion?

Q: Do you believe that you understand the health situation of your child very well? Is this understanding/lack of understanding affecting your child's training to be more independent?

Q: Do you link his/her level of understanding and his/her independence? How do you work on improving his/her cognition or understanding? Do you feel his/her understanding may make him/her dependent?

Q: Regarding rehabilitation training, do you think that professionals have special skills, more than you can do at home? Talk to me about your beliefs here.

Q: Did you find that your child's speech problem causes social interaction difficulties, or do you sometimes push him/her from social interactions to improve speech? Talk to me about your experience in this please.

Q: During your journey in training and working with your child, is there is any skill that you gave up training and decide not to continue? Talk to me about this experience and your thoughts.

Q: Has your child improved in any skill more than you expected? How did this experience affect your belief in his/her improvement and future?

Q: How do you feel about some skills that improve slowly? Does this affect your training at all? Talk about your thoughts here.

Q: Is your child being (girl/ boy) in this society affect his/her independence improvement? Is it positive, negative? talk about your thoughts here.

Questions for specific parents:

Q: Talk to me about his fear, where do you think it comes from? Do you sometimes link his health problem and fear? Do you think it interferes with his independence? How? How do you deal with it?

Q: How do you classify (…..) personality and level of self esteem? Do you think this is going to affect his independence positively or negatively? Is it going to be a motive? how? Explain to me please.

Q: You mentioned (…..) being stubborn before, how do you explain his behaviour? Do you think his stubbornness affects his independence? To what extent and how? How do you deal with him and how do you deal with your other children if they have the same behaviour?

Q: Being a working mother do you think this affected (….) positively of negatively? How? Explain to me further please.

Q: How do find the (housemaid) role in your child's independence – negatively or positively?

Q: How do you deal with his (anger/ fear/ jealous/ aggressiveness)? Do you find it is sometimes accepted or justified? Do you that this may

affect his independence? How? Is this your strategy for dealing with his brothers and sisters?

Q: Do you think that classifying your child (sick or disabled) prevents you from putting pressure on him to improve independence? Or do you try not to focus on this classification? Explain more please.

Q: Does your child's order in the family (if 1st child) affect your motives to improve independence? Talk to me about your thoughts here.

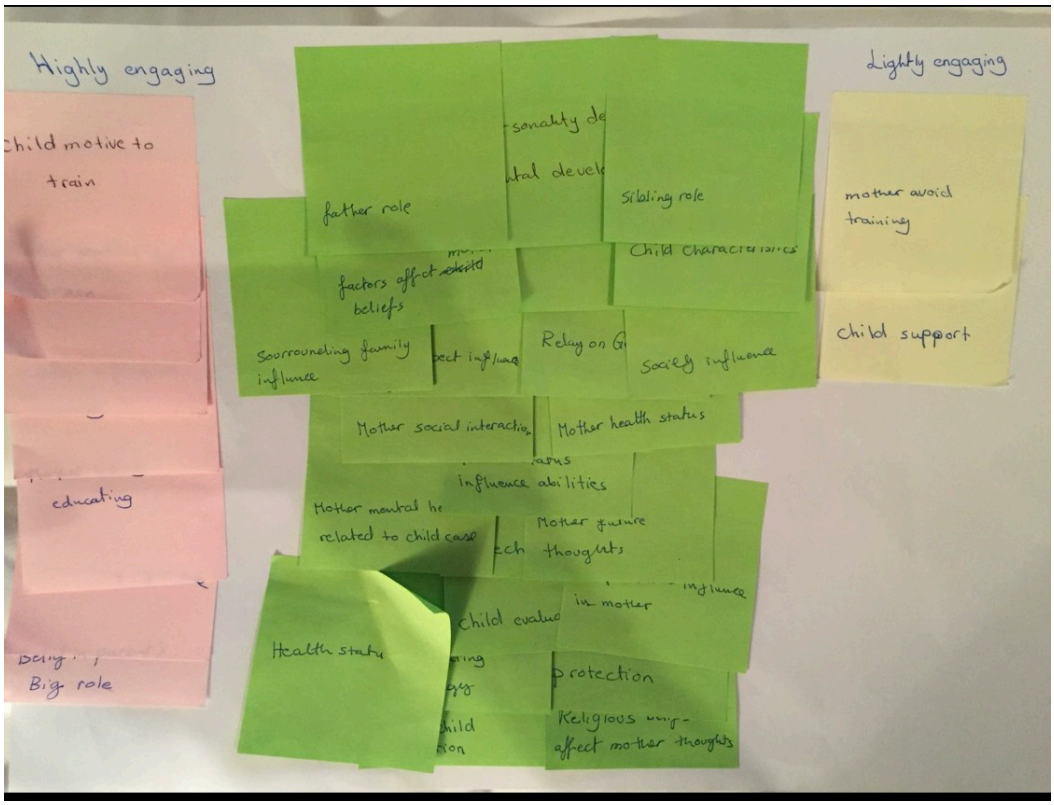
Appendix 6: Interview guide of pilot interviews

The interview will start with appreciation for the acceptance to join the study, and reminding of the mothers' right to withdraw at any time from the study. Then announcing that tape recording will start. Greeting with 'personal information and background', and explaining what do I mean by the word 'belief' to avoid misunderstanding. Then start 'research questions', estimating interview duration is approximate 90 mints and should not exceed 120 mints.

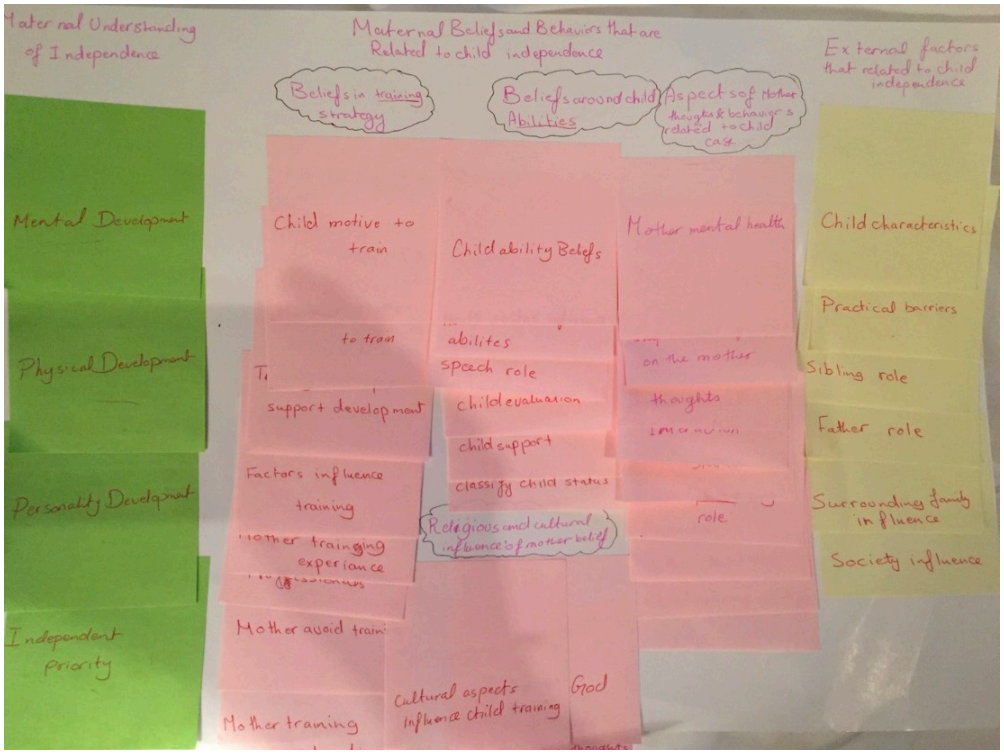
Category	Questions
Personal Information and background	• What is the child age and degree of disability • Mothers' level of education • Mothers' working status • Availability of domestic helper
Starting points **Questions**	• Tell me about your day routine with 'child name', and how you start your day? • Let the mother speck and tell stories of her day and relation with her child • Make sure she talk about her beliefs and justify it regard the main items of self care and mobility skills, they are o Eating o Dressing o Grooming o Toileting o Sleeping pattern o Basic transfer skills o Body transport activity

Appendix 7: Coding process

Coding according to the ladder of engagement



Coding according to mothers' understanding of independence



Appendix 8: Ethical approval from HSJC



JOUD Charitable Women Society
IN DAMM AM
Registered from Govt.Special Security office ,NO (28)
Handy Capped Special Care Center

جمعية جود النسائية الخيرية
للخدمات الاجتماعية بالدمام
مسجلة بوزارة العمل والشؤون الاجتماعية برقم(28)
مركز جود لذوي الاحتياجات الخاصة

لأن التميز غايتنا فلموحنا لايقف

الرقم : ٢٥٩ ٢٥٩ التاريخ : ١٤٣٦/٧/٤ هـ 23-4-2015 AD المشفوعات :

For whom to be concern,

Regard the request from Mrs. Rayya Ibrahim Alkhudair to recruit sample from this organization ' Joud Centre for Day Care, we are pleased to accept her request and approve her data collection from here.

She is welcomed to contact the professionals, and parents and collect data as described in the provided protocol.

Hussa Saleh Al-Bunyan

Principal of Joud Center for Day Care

جمعية جود النسائية الخيرية للخدمات الإجتماعية بالدمام
تأسست عام ١٣٩٨ هـ
مسجلة بوزارة الشؤون الإجتماعية برقم ٢٨

المملكة العربية السعودية _ ص ب 6107 _ الدمام 31442 _ هاتف : 8460153 _ فاكس: 8422916
King of Saudia Arabia_ P.O.Box 6107_ Dammam 31442 Tel: 8460153 _ fax : 8422916 / E-mail –joud.center @ Hotmail . Com