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**Ethnographic study of the religious coping forms of mothers’
experiences of bringing up a child with ASD in Saudi Arabia**

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A thesis presented for the degree of Doctor of Philosophy (PhD)

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March 2019

Declaration

I, Taghrid Alqunaibet, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the text.

Date

Taghrid Alqunaibet

Dedication

To the strong and inspiring women in my life,

My late grandmother, Suad

Mama Ebtisam

Aunties: Faten, Eman and Awatif

My friend Nada

Lennie

Acknowledgments

Jo Billings

Acknowledgement is the hardest when showing one's deep gratitude to the person who offers magnificent mentorship and exceptional guidance. Jo's generosity in giving the time for inspiring discussion and meticulous planning is unmatched. Her dedication, commitment, precision and kindness are such amazing qualities in a supervisor. I would like to express my deep appreciation to my supervisor, Jo Billings for her phenomenal support and encouragement throughout this challenging journey that is unique to her. I am fortunate to have worked with you for this past year, which would not have happened without the helping hand of Claudia Cooper.

Claudia Cooper

"We will make sure to provide you with the right learning experience and the best support." Not only has she delivered on each word with such warmth, kindness and grace but offered her constant mentorship all the way. Claudia has ensured a clear direction was never lost in such a challenging year. I am fortunate to have been guided by you.

It is to you both, Jo and Claudia, that I owe the progress, growth and completion of this academic journey. Such a great team, respectful academics and human beings.

Elvira Bramon

I would like to gratefully acknowledge Elvira for her tremendous support and help in the most dire and critical time of my academic path. Your support and care have never gone unnoticed.

Ayesha Ahmad

My thanks also extend to Ayesha Ahmad for her encouragements and help.

My family

To the late soul of my grandmother, Suad. "Real wealth comes only with education and knowledge" I always heard her say. My memories of her independence, determination and strength are still very much present in my heart.

To mama Ebtisam who supported all my choices, even the ones she was not in favour of. Her love and kindness are two great qualities which she ensured to instil in me. Her endless support and unwavering pride and faith in me have kept me going from strength to strength. It is because of you I am the woman I am today.

To my beloved aunties Faten, Eman and Awatif. I am indebted to you all for the unconditional love, care and support you have shown me since I was a little girl and now as an adult. Your

ethics and principles towards work and life have been instrumental in shaping me. You are my ultimate role models, ones I can only hope to emulate.

To my dearest friend Nada. Your work ethic and determination for success have inspired me to persevere. Your support and encouragement over the difficult years and across the miles while I am completing this challenging study have been invaluable. Without your tireless support, kindness and steadfast trust in my abilities I would not have been able to persist with such a challenge. I am deeply grateful.

To Lennie Kleinberg. Your love, kind heart and clarity have meant so much to me and have been guiding me throughout all those years. Despite our time differences, you were only ever a click away. I am so grateful.

To my beloved Sukkar.

Professional contacts in London

I am so grateful to Raya Ahmed for her tremendous contribution in the arduous task of translation. I am grateful for the long hours, the commitment and the effort you put towards the work.

I am also grateful to Lucy Webster for proofreading and editing. Your help is so much appreciated.

Staff and professional contacts in Saudi

I am also grateful to all the directors, teachers and staff of the autism schools and centres who agreed to take part in this study. They provided me with the space to start from and offered me their knowledge and support throughout my fieldwork.

Special thanks go to Manal Algenasi who never hesitated to help me during the intense period of transcribing and editing with such speed and dedication. Her help continued even after leaving the fieldwork and went back to London.

My deepest appreciation goes to my colleagues in the field back home who lent their support and connections to open some closed doors.

Saudi Mothers of children with autism

Finally, I am indebted to you for welcoming and including me in your ongoing journeys with your children. I am honoured and humbled by the trust you have placed in me. Without the stories you shared with me and the insight you provided, I would have never been able to complete this thesis with such deep and rich understanding.

Abstract

Autism is increasing in prevalence and has become a global concern. It has been long recognised that the presence of autism can have a significant impact on family members and that autism can result in greater parental stress than other disabilities. A growing recognition in research has emerged about the religious beliefs held by the families of children with disabilities due to the significant role played by religion in shaping parents' interpretation and understanding of the disability. Therefore, religious parents may draw upon their faith to help them cope, make sense and construct meanings around their child's disability.

A gap exists in the literature regarding the needs, concerns, and overall experiences of Arab Muslim parents of children with autism. A scarcity in the literature examining autism in the Gulf region has been acknowledged with no research to date in Saudi Arabia which has investigated the burden of autism on the family, child and society. What little research there is in this area has predominantly explored the experiences of parents in Western societies and mostly from a quantitative paradigm. We quite simply do not yet know how autism impacts on families in Gulf countries such as Saudi Arabia. Up until this point it has been quite unfathomable to ask about such experiences in this context, particularly of those most involved in their child's care; mothers.

This ethnographic study therefore set out to explore how Saudi mothers caring for a child with autism recognized and understood autism, what their cultural beliefs and

understanding of autism were, and how they coped and adapted with their concerns, worries and needs regarding their children.

Two ethnographic methods were employed in the study; participant observation and qualitative interviews. Data analysis showed that mothers' responses clustered around particular themes. Three major themes emerged from the data (*Autism invisibility within the wider society and the difficulties of getting and dealing with the diagnosis; Autism causality and the explanatory frameworks used by mothers to understand the condition; Various internalised and externalised stigmas associated with autism and the relationship of the condition to disability and disablement*), each of which offered insight into Saudi mothers' unique experience of coping, adapting and bringing up a child with autism. *Mothers' Unfinished journey*, is the overarching global theme within which all three major organizing themes and sub-themes were grouped. The findings of this study are discussed in detail, as well as the implications of the findings and recommendations for future research.

Impact statement

The impact and benefits of this study can be highlighted in the following three areas:

The impact of access and raising awareness

This is the first study of its kind to access the views of mothers of children with autism in Saudi Arabia, in a culture where women's voices are rarely heard and mothers of children with disability doubly discriminated against. Accessing these mothers and hearing their narratives and stories was significant and unprecedented. This study has shed light upon the cultural invisibility of these women and their children, as well as raised awareness of their ongoing struggles and previously hidden concerns. Prior to this study, Saudi mothers' voices were not present even with the limited body of currently existing research on autism in Saudi. Now we can begin to understand how they try to make sense of and cope with raising a child with autism in Saudi culture.

The impact of this study in Saudi and beyond

The impact of this study in Saudi Arabia itself may be limited by significant barriers to its dissemination in that context. Nevertheless, it can still have a significant impact in Western countries by enabling a much better understanding of how Saudi people experience and understand their children's disabilities. It will provide information and context for Western professionals on the ways in which Saudi culture shapes the thinking, meaning and coping with autism amongst the families they may work with. The impact of this study may go further and extend to other Muslim parents, as Muslims

share an overarching collective religious culture, whereby they apply religious meaning to any illness.

The impact of pioneering qualitative and ethnographic research in Saudi

Finally, this study has demonstrated that a qualitative and ethnographic approach can indeed be accomplished in Saudi Arabia. Despite all the warnings I received from day one of my fieldwork with respect to this being a culturally unacceptable methodology, these claims have proved to be unwarranted. Whilst it was not without challenges, this study has shown that qualitative interviewing and ethnography can be acceptable in Saudi Arabia, and could therefore potentially be achievable in many other previously inaccessible Muslim cultures. Therefore a particularly important impact of this study is that it paves the way for more research of this type in previously deemed impenetrable cultures.

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Introduction to the thesis

The introduction to this thesis is separated into three constituent parts. In the first chapter, Background, I will set out the key concepts, theories and literature relevant to our understanding of the impact of raising a child with autism on parents and religious coping. In the second chapter I will outline the Socio-Political Context of the Research. In the third chapter, at Home in the Field, I will reflect on my own background and motivations for conducting this research and discuss some of the challenges of engaging in qualitative and ethnographic field work in this context.

In the fourth chapter, I will outline the specific research approaches and methods that have been applied to the study. In addition, a discussion is provided of the underlying research philosophy, outlining the relationship between the methodological theory and the practical aspects of the study. Finally, this chapter highlights the important ethical issues that have informed the research process.

The results of my PhD are presented in chapter five, where I will discuss the combined thematic analysis that comes from the participant observations fieldnotes and the in-depth qualitative interviews.

In the sixth chapter, I discuss the meaning of the research findings and explain their value in light of the literature. I critically examine the findings and present what has been learnt from the work. I will provide and justify certain key recommendations to be made for children and their mothers. This is followed by a brief outline of the limitations inherent to this research and potential opportunities for future work.

Chapter 1: Background

In this chapter I will outline the concept of Autism Spectrum Disorder (ASD) and explore the impact of this diagnosis on parents. The cultural and social context of autism will be discussed as well as the stressors placed on parents from raising a child with autism. Religion as a form of coping will be discussed broadly, with specific attention to children with autism and/or children with disabilities.

Definition and Epidemiology of Autism Spectrum Disorder (ASD)

In 1943, Dr. Leo Kanner wrote the first known paper that included the term “autism”. He applied this term to describe of a group of eleven children whom he had observed as self-centred children with severe social, communication, and behavioural problems. Hans Asperger (1944), unaware of Kanner’s earlier report, used the term “autistic psychopathy,” which also described marked disturbance in social interactions. Latterly Wing (1997) described the triad of autism as a form of impairment in three major areas: social communication, social imagination, and social development.

Autism Spectrum Disorder (ASD) is considered (in Western medical science) to be a brain-based, usually genetically determined, developmental disability, which is characterised by early onset (before 3 years of age) and by delays and impairments in three critical areas of development: social interaction (the forming of relationships and sharing of interests and emotions); communication and language (both verbal and non-verbal); and a restrictive repertoire of behaviours, interests and activities (Turk, Graham, & Verhulst, 2007).

According to Ritvo, Freeman, Pingree, Mason-Brothers & Jorde (1989), the behavioural signs of ASD usually appear before the age of three, although autism is believed to exist from birth or very early in development (National Research Council, 2001). Delays in language development and communication deficiency are considered to be a characteristic and presenting features of children with autism (Howlin & Moore, 1997; Stone, 1997; Cumine, Dunlop, & Stevenson, 2010). ASD has a male-to-female ratio of about 4 to 1 (Fombonne, 2003) and it is estimated that 60 to 75 percent of children with autism are affected by comorbid intellectual disability (Bryson, Clark, & Smith, 1988; Bertrand, Mars, Boyle, Bove, Yeargin-Allsopp, & Decoufle, 2001).

Medical Model

Both Kanner and Asperger implement a medical model to explain autism. The medical model aims for symptom reduction and elimination of conditions, based on deficits understood to cause functional impairment in major life activities (American Psychiatric Association (APA), 2000; Baker, 2011). According to Anckarsater (2010), in the absence of biological markers, psychiatry mostly determines deficits on the basis of behavioural deviation from the average and what is considered normal. This is how autism is defined in psychiatry and cognitive psychology (APA, 2000, Baron-Cohen, 2003, 2008; Firth & Hill, 2003). In turn, such classification systems lean towards omitting advantageous behaviours, the reasons for behaviours and society's role in determining and defining appropriate behaviours (APA, 2000; Armstrong, 2010; Baker 2011). As a result, the medical model does not differentiate between conditions resulting from poor-person environment fit and diseases that cause deterioration and

even death (Baker, 2011). By viewing people as sick or having reduced capacity, the medical model often grants the ability to delegate care decisions, especially for children and people considered severely disabled, to professionals and family members (Baker, 2011; Silverman, 2012). In the Western world, commonly, parents of autistic children align with the medical model with the intention of cure, recovery, and of at least a more normal presentation (Chamak, 2008; Bagatell, 2010; Jordan, 2010).

Many parents, professionals and the lay public support the medical model by labelling autism as a disease and even as an epidemic, due to the rise in the number of diagnoses and belief in contributing environmental factors (Bagatell, 2010; Russell, Kelly, & Golding 2010). Consequently, the epidemic claim has been used by some parent advocates to argue for unnatural causes like toxins, and an urgent need to screen, treat and try to eradicate these risk factors as a public health crisis (Baker, 2011). Following this movement, basic science research, which often links illness to causation, has received the majority of autism research funding in the United States (Singh, Illes, Lazzeroni & Hallmayer, 2009; Bagatell, 2010).

To date, the majority of published research in autism has developed from areas linked to clinical practice, therefore there has been an almost total focus on the condition as involving deficits (Milton & Bracher, 2013). While there are indications that this approach is beginning to change (Mottron, Dawson, Soulieres, Hubert, & Burack, 2006; Baron-Cohen, Ashwin, Ashwin, Tavassoli, & Chakrabarti, 2009) to an understanding of autism as including a variety of potential strengths and limitations, this dominant medical view still guides mainstream research, based on the assumption that

autism is consisting entirely of deficits that require medical intervention (Milton & Bracher, 2013).

In summary, the medical model of autism sees it as an illness which is defined by deficits from 'normal' behaviour and people with autism are seen to lack the essential skills required for the establishment and maintenance of their community (Bagatell, 2010). However, autistic self-advocates, also known as the autism rights movement, have argued that autism represents broader neurodiversity in the population and celebrate autism as inseparable from their identity. They also challenge efforts to find a 'cause' and a 'cure' for autism (Jordan, 2010; Baker, 2011).

Neurodiversity Movement

The medical model of understanding a disability commonly concerns diagnosis, aetiology, causes and treatment. As aforementioned, this model considers autism a pathology for which a diagnosis and cure should be sought. However, the neurodiversity movement seeks to provide a culture in which autistic people feel pride in a minority group identity and provide mutual support in self-advocacy as a community (Ortega, 2009; Jordan, 2010; Jaarsma & Welin, 2012). The neurodiversity movement also celebrates autism among other neurological conditions as a natural variation with conferring rights, value, recognition, and acceptance of the neurodiversity condition (Jaarsma & Welin, 2012).

According to Chamak (2008) and Ortega (2009), the neurodiversity movement arose initially online in response to the perceived marginalisation of autistic people by organizations run by parents of autistic people. Neurodiversity is considered a political

identity among self-advocates with autistic spectrum disorders, other disabled people and activists. They promote a proud identity as opposed to focusing on treatment towards a cure (Bagatell, 2010; Brownlow, 2010). Many self-advocates fear that cause-oriented research will inevitably lead to the search for genetic prevention of autism (Ortega, 2009; Orsini & Smith, 2010; Baker, 2011). Additionally, they have voiced concerns about prioritising causation research which diverts resources away from supporting individuals themselves (Robertson, 2010; Pellicano & Stears, 2011).

While neurodiversity advocates tend to adopt a form of the social model of disability, distinguishing between a biological, underlying condition or way of being (autism) and disability rooted considerably in living in an inaccessible social and political infrastructures (Baker, 2011), they still broadly understand autism as caused by biological factors and celebrate it as a part of natural human variation (Ortega, 2009; Armstrong, 2010). They regard the strengths, differences, and weaknesses associated with autism as central to their identity (Ne'eman, 2010; Robertson 2010). A key aspect of the neurodiversity claim is linked to the idea that there is indeed neurological “or brain-wiring” differences amongst the human population and being autistic is one example (Jaarsma & Welin, 2012). That is, being neurodiverse or neurotypical (“normal”) are just different ways of existing as humans (ibid).

It is also important to shed light upon the fact that autistic self-advocates/neurodiversity proponents tend to favour the usage of identity-first (e.g., “autistic person”) instead of using person-first (e.g., “person with autism”), which might seem to perpetuate stigma in the eyes of the research community (Ortega, 2009; Bagatell, 2010; Orsini & Smith, 2010). From a neurodiversity perspective, behind using

such a term (person with autism), is the implication that there is a normal person trapped behind the autism (Jaarsma & Welin, 2012). Such a term carries with it the idea that a person is somehow separable from autism, which negates one aspect of the neurodiversity movement of being accepted as they are with varying degree of neurobiological impairment and neurological diversity (Jaarsma & Welin, 2012; Krcek, 2013). The second aspect of the neurodiversity claim is related to their rights, non-discrimination and other more political issues. Overall, the neurodiversity movement aims to provide a culture where autistic people feel pride in a minority group identity and provide mutual support in self- advocacy as a community (Ortega, 2009; Jordan, 2010; Baker, 2011).

The social model of disability

It is important to mention that the new movement established by autistic individuals and known as *neurodiversity* derives its roots from a social model of disability which challenges the dominance of the medical model of autism.

The social model of disability reconstructs disability as a social and political process (Silvers, 2010; Krcek, 2013). According to the social model, it is society that disables the individual. Thus, the social model focuses on functioning as an interaction between a person and their environment, stressing the role of society in labelling, causing, and/or maintaining disability within the society (Silvers, 2010; Krcek, 2013). The term social model of disability was first coined in literature by Oliver (1986) as he interpreted the *Foundational Principles of Disability* which written by UPIAS in 1967 (see Oliver, 1986; Oliver, 2013, for a review).

Impact of diagnosis and caring for a child with autism

It is well known that caring for a sick relative or friend can be a very distressing experience and an ongoing crisis (Pargament, 1997). Illnesses have been reported to interrupt routines, drain finances, separate families and create situations of dependency or vulnerability that bring about existential and spiritual concerns to both the affected and the concerned individuals (Dein & Stygall, 1997). As people become ill, they and their relatives will be exposed to different stressful experiences over the course of the changes that the illness may bring about in their lives.

In the same way, the diagnosis of a disabled child is likely to put any family under lots of difficulties and stress. A child being diagnosed with autism is a specific challenging event faced by many parents. Hearing such a phrase as “*your child has autism*” is likely to have a profound impact on any parent (Freeth, Milne, Sheppard & Ramachandran, 2014). Autism is known to be a lifelong developmental disability, which prevents those affected by it from reaching usual developmental milestones and participating in some of the most rewarding aspects of human experience such as; language, communication, and the ability to give and receive love, all of which are markedly impaired in individuals with autism (Marshall & Long, 2010). Arguably, though, it is not the individual with autism who feels these losses and impacts so severely, rather it is his/her parents (Marshall & Long, 2010).

When compared with other childhood disorders, it has been argued that autism poses a particular threat to the psychosocial well-being of the parents (Dumas, Wolf, Fisman & Culligan, 1991; Gray & Holden, 1992; Gray, 2006). Parenting a child with

ASD is not an easy task for many different reasons. Children with ASD commonly experience a variety of complex development and behavioural problems (Bolte, Westerwald, Holtmann, Freitag, Poustka, 2011). ASD manifestations vary widely as well, and can include sleeping problems, eating disorders, fears/phobias, and aggressive behaviours (Giovagnoli et al., 2015).

Autistic children usually meet physical developmental milestones and therefore appear to be physically “normal”, yet they suffer from a disability that is extremely pervasive and which affects many areas of their life (Gill & Liamputtong, 2009). Such a “normal” physical appearance combined with the relative lack of public knowledge about the disorder means that their parents might experience hostile public reaction to their child’s inappropriate behaviour (Gray, 1993, 2002; Gill & Liamputtong, 2009). Therefore, parents are often confronted with challenges at a personal and social level across various contexts, an increase in personal stress, effects on interpersonal relationships and increasing isolation (Altiere & von Kluge., 2009; Divan, Vajaratkar, Desai, Livers, & Patel., 2012).

Consequently, the role of a child’s disability on parental stress and coping has been investigated by researchers. It has been shown that there is greater stress, more health problems, and higher levels of depression reported in parents of children with developmental disabilities when compared with parents of non-disabled children (Quine & Pahl, 1985). In more recent studies, mothers parenting a child with autism have been found to have poorer mental health, poorer physical health and lower quality of life when compared to mothers raising typical developing children or children with other health or developmental impairments (Olsson & Hwang, 2001; Hastings, Kovshoff, Ward,

Espinosa, Brown, Remington, 2005; Allik, Larsson & Smedje, 2006; Mugno, Ruta, D'Arrigo & Mazzone, 2007). Much evidence also suggests that the parenting burden falls more heavily on mothers than fathers (Moes, Koegel, Schreibman, & Loos, 1992; Gray, 1993; Davis & Carter, 2008)

Researchers have asserted that parents of disabled children usually respond with shock, frustration, and grief to the initial diagnosis of the disability (Fortier & Wanlass, 1984; Ferguson, 2002). However, in the following years parents' adaptability becomes more adjustable to the condition, yet the effects still continue as the child grows and develops (Kearney & Griffin, 2001). This is partly because parents of children with disabilities and behavioural problems constantly keep adapting themselves to specific stressors that accrued throughout the childhood and adulthood years of the child (Floyd & Gallagher, 1997).

The Social Context of ASD

ASD is a lifelong disorder, with impairments permanently affecting the individual and posing many challenges to the individual's family across the course of their lives. ASD has been shown to lead to considerable functional and financial impact on both the individuals and their family (Jarbrink & Knapp, 2001; Howlin, Goode, Hatton, & Rutter, 2004), which means extensive support from the education, social welfare and health care systems may be required.

Typically, a child with ASD will require significant amounts of parental time and energy, arguably over and above other children. For example, it has been shown that severe behavioural disturbances in addition to lack of social competence and

responsiveness cause a significant increase in parental stress (Cameron, Dodson & Day, 1991; Olsson & Hwang, 2001). This drain of resources can affect the marital relationship and functioning of the family members (Rodrigue, Morgan, & Geffken, 1990), lower the level of intimacy within the marriage, and causes greater levels of marital discord (Olsson & Hwang, 2001; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). Parents of children with autism report greater levels of depression (Olsson & Hwang, 2001), a higher level of stress (Benson, 2006), and usually lower overall well-being (Ekas, Whitman, & Shivers, 2009) compared to parents of children without developmental disorders. Obtaining a diagnosis, finding appropriate treatment and educational programs and struggling with the continuous financial burden of paying for these services are other ongoing challenges faced by parents of children with ASD globally (Whitman, 2004; Gray, 1993, 2002; Cavkaytar, Batu & Cetin, 2008; Alariefy, 2016; Alnemaary, Aldhalaan, Simon-Cereijido & Alnemaary, 2016).

Culture and Autism

When people are faced with a life changing event, family and cultural values are likely to play a vital role in how they interpret the new situation (Pitten, 2008). Family cultural background similarly impacts on decisions made by families about autism diagnosis and treatment (Ennis-Cole, Durodoeye & Harris, 2013) and the meaning parents attach to their children's symptoms and their associated beliefs about the best care for them can be understood within the parents cultural context (Mandell & Novak, 2005). Culture, according to Helms & Cook (1999), can be defined as "*the values, beliefs, language, rituals, traditions, and other behaviours that are passed from one*

generation to another within any social group". Culture therefore shapes individual and family beliefs about disability in general and autism in particular (Ennis-Cole et al., 2013).

Pargament is considered to be one of the experts in the psychology of religion and spirituality. His work represents a major theoretical and empirical contribution to both the psychology of religion and clinical/counselling psychology as well as to other fields as well (McFadden, 1998). He has extensively published on religion's role in mental health (American Psychological Association, 2013). According to Pargament (1979), an individual's experience of illness cannot be considered in isolation from the cultural context where it happens, particularly when it is a life changing or life limiting illness, such as autism. In other words, we cannot separate parenting of children with autism from the religious and social context in which this parenting occurs.

Although illness and suffering are a universal human experience, such experience comes to be endowed with specific cultural meaning. Paying attention to understanding the nature of the cultural knowledge brought to illness, how such a knowledge is employed in assessing the illness, and what considerations are applied to bear in making treatment decisions (Garro, 2000), are all crucial elements in understanding how individuals in specific cultural settings make sense of and deal with illness. Therefore, it is important to recognise that cultural understandings do not function in a top-down deterministic manner, rather, are better seen as tools which both enable and constrain interpretative possibilities available to navigate the ambiguity surrounding illness and other experiences (Garro, 2000).

In addition, culture is the lens or template that people from different cultural contexts and traditions will utilise to construct, define, and interpret reality. As a result, they will define and experience reality in very different ways. Thus, even the experience of mental disorders will vary across cultures because they cannot be separated from the context of the culture in which they occur (Marsella & Yamada, 2000). For example, the meaning parents attach to their childrens' symptoms and their associated beliefs about the symptoms, causes, prognosis, and most appropriate path of care can be described within the context of that specific culture. After all, even the impact of disability is influenced by the sociocultural context in which the individual or the family lives (O'Hara & Bouras, 2007).

Different cultural models of child rearing and child development exist in every society, in turn the attribution of meaning and understanding e.g., intellectual disability (ID) would vary greatly across cultures (ibid). According to Skinner & Weisner (2007), when confronted with a child with developmental difficulties, a child's parents are confronted with a process of meaning-making stemming from the available cultural models of 'normal' and 'abnormal' child development, which will inform their own understanding of their child's delays. Regardless of parents' reported satisfaction with the information received from health professionals, they are likely to have their own alternative interpretations grounded in the cultural context in which they live (Skinner & Weisner, 2007).

Within the Saudi Arabian cultural context where this research took place, religion is the core and the fabric of all life. Simply, it is a way of life. While religion is considered as one of many cultural values in numerous societies, in Saudi, religion is

the most significant influential resource brought to the forefront of all life matters by most of the people, regardless of how serious or trivial that matter is. As a result, its significance can be seen in the diagnosis, treatment, and welfare of families with autistic individuals as well as with all illnesses and diseases.

Understanding culturally specific responses to coping with experiences such as having a child with autism in Saudi Arabia is therefore essential in understanding the different and unique ways in which mothers comprehend, construct, and cope with autism.

Stressors Experienced by Families of Children with ASD and their Coping Strategies

ASD is regarded by mainstream research as a severe disability contributing to higher psychological distress among parents than what is experienced by parents caring for children with a non-ASD developmental disability (Randall & Parker, 1999; Dyches, Wilder, Sudweeks, Obiakor & Algozzine, 2004; Estes, Hus & Elder, 2011; DePape & Lindsay, 2015). An uncertain future for children, educational barriers, a continually contested diagnosis with variable social acceptance, and limited treatment access have been argued to contribute to parental stress (Gray, 1993; Giarelli, Souders, Pinto-Martin, Bloch & Levy, 2005). Behavioural difficulties and associated restrictions on their own personal lives are some of the factors that have been shown to contribute to a higher risk of depression particularly in mothers of children with ASD when compared, for example, with mothers of children with intellectual disability who do not have autism (Lainhart, 1999; Olsson & Hwang, 2001; Boyd, 2002).

The stressors experienced by families of children with ASD (e.g., parental depression and anxiety, difficulties in daily management of the child, financial worries, and concerns over adequate educational and professional resources) have been shown to be significantly greater when compared with families of children with other disabilities (Holroyd & McArthur, 1976; Rodrigue, Morgan, & Geffken, 1990; Gray, 1993). Also, when compared with parenting typically developing children, parents of children with autism are at greater risk of increased stress and mental health problems (Totsika, Hastings, Emerson, Lancaster & Berridge, 2011).

The complexity of bringing up a child with ASD has been associated with important changes in family dynamics (Altiere & Von Kluge, 2009; Cridland, Jones, Magee & Caputi, 2014). Researchers have also highlighted the emergence of physical and emotional health problems associated with high levels of the overload and burden experienced in the parents of children with autism (O'Halloran, Sweeney & Doody, 2013; Gatzoyia, Kotsis, Koullourou & Goulia, Carvalho, Soulis, Hyphantis., 2014; Giovagnoli, Postorino, Fatta, Sanges, De Peppo, Vassena, De Rose, Vicari, Mazzone, 2015; Karp & Kuo, 2015). Parental feelings of disbelief, anxiety, distress, or sadness are frequent and common during the diagnosis of autism in a child and the following months (Ludlow, Skelly & Rohleder, 2012). From the above, the challenge and demand for raising a child with autism have clearly been documented in previous and recent research.

Other evidence has, however, pointed to less of a difference between stress experienced by parents of children with ASD compared to other parents, and not all parents report feeling that their lives have been disadvantaged by ASD, with some

studies showing that, on the contrary, many may perceive their lives with disabled relatives as mutually beneficial (Simons, 1987). For example, in a study by Koegel, Schreibman, O'Neill, & Burke (1983), different aspects of parental functioning in 49 mothers and fathers of children with autism were studied. Their results did not find any differences in stress levels and psychological functioning when these families were compared with control families of children without autism. This finding is similar to more recent studies by Benson (2006) and Benson & Karlof (2009), in which they found that parents of children with autism experienced relatively few significant mental health problems. However, it was clear that parents varied substantially in their responses and ability to positively respond to the challenges linked to their child's autism.

From the above it can be seen that parents in some studies have been shown to experience significant mental health problems associated with raising a child with autism, whilst in other studies, parents have been reported to have experienced fewer difficulties. On the one hand, some parents reported experiencing significant psychological outcomes including increased levels of depressive symptoms (Carter, Martinez-Pedraza & Gray 2009; Ingersoll & Hambrick, 2011) with overall lower levels of well-being (Eisenhower, Baker & Blacher, 2005). On the other, some parents were found to experience fewer difficulties or even experience positive gains as a result of raising a child with autism or other disabilities (e.g., finding meaning, personal growth and increased patience and empathy) (Hastings & Taunt, 2002; Scorgie & Sobsey, 2000; Pakenham, Samios & Sofronoff, 2005).

Less research has, to date, attended to differences between fathers and mothers and the potentially differential impact on each, especially given that in most cultures

mothers are usually the primary caregivers and the parent who often bears most of the most everyday responsibilities for childcare (Marcenko & Meyers, 1991; Moes, Koegel, Schreibman, & Loos 1992; Duvdevany & Abboud, 2003). When compared to fathers, mothers of children with autism were reported to have higher level of stress and depression (Moes et al., 1992; Davis & Carter, 2008). Due to the primary caregiver roles played by mothers of autistic children (e.g., spending more time with the child and dealing with day-to-day behavioural issues), their emotional wellbeing was found to be more severely affected by their child's autism than the fathers (Gray, 2003). Therefore, the experience of caring for a child with a disability may potentially be even more impactful on mothers (McLinden, 1990) with less practical support offered by the child's father (Young, 1997). Such impact on mothers may be especially strong in traditional societies (Alariefy, 2016; Ilias, Liaw, Cornish, Park & Golden, 2017; Ang & Loh, 2019) where fathers are still seen as the financial provider for the family and mothers burden more of the emotional and practical aspects of childcare (Crabtree, 2006; Gray, 2003; Wang, Michaels & Day, 2011; Alariefy, 2016; Ang & Loh, 2019). However, to date little research has explored the differences between fathers and mothers, particularly in non-western cultures and as yet none has explored potentially more positive outcomes.

Coping

How well families adapt to having a child with autism and face potentially continuous challenges brought about by raising such a child may depend on the different coping strategies they utilise, the resources available within the family (Tarakeshwar & Pargament, 2001), and the availability of social support (Boyce, Behl,

Mortensen, & Akers, 1991; Boyd, 2002). A potentially important resource and coping strategy for a family is religion, as a growing number of studies have indicated how religion offers a variety of coping mechanisms that could help people during stressful times (see Pargament, 1997, for a review). It is to this that I will now turn my attention, after briefly providing some broader context around the concept of coping.

The term “coping” in the psychiatric literature refers to the process through which individuals try to understand, comprehend, and deal with significant personal or situational demands. Coping has been defined as:

- *“All of the mechanisms utilized by an individual to meet a significant threat to his psychological stability and to enable him to function effectively”* (Friedman, Chodoff, Mason, & Hamburg, 1963, p. 616).
- *“Any response to external life strains that serves to prevent, avoid, or control emotional distress”* (Pearlin & Schooler, 1978, p. 3).
- *“Behaviors that are employed for the purpose of reducing strain in the face of stressors”* (Hobfoll, 1988, p. 16).
- *“The use of strategies for dealing with actual or anticipated problems and their attendant negative emotions”* (Aldwin, 1994, p. 107).

These different definitions of coping illustrate that coping is an adaptive response in the face of internal or external stressors. Coping, in a general sense, means that in difficult situations people use available personal resources in an attempt to manage effectively and try to resolve stressful situations. Coping is therefore an encounter between individuals and their experience of challenging stressors in life. Importantly, in the process of coping, individuals may employ different systems and are influenced by family, organisational, institutional, community, societal, cultural, and social relationships, which may assist or create obstacles of their own (Pargament, 1997).

The stress and the different coping processes linked with parenting a child with

autism have been the focus of much research, but the majority of this research stems from the positivist paradigm and focuses on traditional ways of conceptualising stress and coping (Marshall & Long, 2010). For example, Lazarus and Folkman's (1984) model of stress and coping has long dominated the field resulting in different and alternative conceptualisations being slow to be acknowledged (Benson, 2010; Marshall & Long, 2010).

Lazarus and Folkman (1984), defined coping as “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (p. 141). Based on Lazarus and Folkman's (1984) model of stress and coping, researchers have often grouped coping methods into two general categories, *problem-based coping* (strategies aimed at solving the problem or doing something to change the source of the stress) and *emotion-based coping* (strategies aimed at reducing or managing feelings of distress associated with stressor) (Benson, 2010).

The distinction between problem- focused and emotion-focused coping has served an important heuristic purpose in stress research, yet evidence suggests that it has oversimplified how people with adversity cope (Lazarus, 1996; Skinner, Edge, Altman & Sherwood, 2003). Also, many important and different coping methods such as the use of social support, do not fit clearly into either the problem- or emotion-focused coping conceptualisation. According to Benson (2010), coping strategies have been situated as one mechanism by which individuals respond to threats of stress including stressors linked to parenting a child with autism. In his review of the existing literature on coping by parents of children with autism, Benson (2010) stated that the

existing literature is limited, with very little known about the underlying structure of coping strategies used by the parents of children with autism, and many key issues left unresolved apart. Benson (2010) highlighted one exception, a study carried out by Hastings, Kovshoff, Brown, Ward, Degli Espinosa & Remington (2005). It is the only study reported by Benson which examined the structure of coping methods implemented by parents of children with autism in the UK. The study used an explanatory factor analysis to classify the coping methods used by the parents. Based on the Hastings et al., (2005) analysis of parents' responses on the *Brief COPE*, four consistent coping dimensions were identified. They are termed as active avoidance coping, problem-focused coping, positive coping, and religious/denial coping. The first two closely corresponded with Lazarus and Folkman (1985), emotion and problem focused coping categories which is commonly used in stress research. The other two are viewed as being uniquely specific to circumstances relating to parenting a child with autism or other disability (see Hastings et al., (2005), for a review).

Coping is a complex and multi-faceted concept, but one facet of particular interest in this study, is religious forms of coping. In Islamic culture, the phrase "e.g., it is the will of Allah" is utilised repeatedly to help explain and accept many life circumstances and difficulties. Many cultures attribute physical, psychiatric or developmental disorders to spiritual and supernatural causes where parents may use their beliefs as a way to make sense of why disability has happened to their own child and to come to an understanding about themselves and their child's impairments through a religious framework (Dura-Vila, Dein & Hodes, 2010). For example, the birth of a child with an intellectual disability may evoke positive attributions such as being a

gift from God or a divine blessing (O'Hara & Bouras, 2007). Thus, religion, or the belief system of any culture, is one of the fundamental aspects that will influence how people coped with challenging life events, such as having a child with autism. This is especially true if the culture happens to adhere to a religiously conservative system like Saudi Arabia where parents of a disabled child may draw upon their religion to understand and frame their child's disability.

What is Religion

A single definition of religion is very difficult if not impossible. As Wulff (1997) argues, a "*satisfactory definition of religion has eluded scholars to this day*".

Furthermore, King & Dein (1998) suggest that there are as many definitions of religion as there are writers on the topic. For example, Hood, Hill & Spilka (2009) admitted that they are in a dilemma when it comes to the definition of religion and cited the sociologist J. Milton Yinger (1967), who maintained that "*any definition of religion is likely to be satisfactory only to its author*" (p. 18), and also cited a noted psychologist of religion, George Coe (1916), who said that he would "*purposely refrain from giving a formal definition of religion...partly because definitions carry so little information as to fact*" (p. 13). Thus Hood et al. (2009) refrained from defining religion and instead said that religion performs many functions for many different people. Nevertheless, Pargament (1997), defined religion as a process; "*a search for significance in ways related to the sacred*" (p. 32). In addition, Loewenthal (2000), suggested that major religions have common features:

- Their existence in a non-material reality (i.e., spiritual)
- Their purpose is to increase harmony by doing well and avoiding evil

- The source of existence is also the source of moral directives (in the case of monotheistic religion, it is God)
- Social organisation is involved for communicating these above ideas.

In short, common features of religions thus include beliefs and behaviours about spiritual reality, God, morality, purpose, and finally the communication of all the above.

Islam is the religion with which the present study is concerned. Islam as a religion shares the main features mentioned above. Also, like other religions, its defining features are expressed in a unique set of regulations which lead followers to achieving their ultimate religious goals. Since all religions have a spiritual dimension, it can be assumed that religiosity is spiritual in nature, however, spirituality is not necessarily affiliated with an institutionalised religion. Thus, religiosity can be understood as the influence of religion on a person's life.

Hood et al., (2009), explained that their position is to search in mind, society and culture for the nature of religious thinking and behaviour and not to study religion per se. Where the sociocultural context is the external foundation for religious beliefs, attitudes, values, behaviours and experiences.

Religion as a Strategy for Coping

Previous research has consistently demonstrated that people may turn to their deity for support and utilise available religious resources to cope with a personal or national tragedy.

For some people, religion brings a symbolic meaning and purpose to their existence as well as a certainty about the ultimate end of life, which every organised

religion has in common. Geertz (1966) argued that the giving of meaning is the most essential function of religion. Freud (1927-1961) argued that people turn to religion out of a sense of helplessness. He also asserted that religious beliefs and practices provide people with relief from unbearable tension and anxiety. Relief may arise from helping people to cope with what is causing their anxiety or allow them to see their situation in a clearer perspective. Pargament (1997), described other purposes of religion, as some people look to religion for meaning, some for intimacy, some for hope, some for problem-solving, self-esteem, and some for fulfillment of physical health. For example, understanding the value of prayer for rapid recovery from illness is a foundational element in the religious services of most faiths (Conway, 1985-1986; Segall & Wykle, 1988-1989).

These studies highlight the frequent use of religion in positive coping with negative events. However, these studies also highlight the need for a more comprehensive assessment and deeper understanding of the significance that the role religiousness has for coping and the mechanisms by which it works (see Pargament, 1997; Pargament, Smith, Koenig & Perez, 1998; Hood, Hill & Spilka, 2009, for a review).

Religious and spiritual involvement might provide additional ways of dealing with life's stressors by also complementing nonreligious coping. Pargament, Ensing, Falgout, Olsen, Reilly, Haitsma & Warren (1990), have described three ways in which religion can be involved in the coping methods and each serves various ends:

- As a component part of each of the elements of the coping process. For example, ceremonies such as baptism, marriage, divorce, and funerals are all

religious markings of significant life events. Religious appraisals may also be at hand to explain these life events. Tragedies can be analysed as God's plan, a punishment from God, or unintended by God (Cook & Wimberly, 1983; Jenkins & Pargament, 1988).

- Religion can contribute to the coping process by discouraging unhealthy practices. For example, research has found life events such as; drug and alcohol abuse or non-marital sexual activity to be reduced by increased engagement with religion (Spilka, Hood, & Gorsuch, 1985).
- Religion can be a product or a consequence of the coping process, for example, increased faith following the birth of a child or a loss.

In addition, Pargament (1997) has identified other forms of religious coping, such as benevolent religious appraisal, seeking support from clergy, seeking spiritual support, discontent with congregation and God, negative religious reframing, and expressing interpersonal religious discontent. He explained that some forms of religious coping (e.g., perceiving illness as the will of God or as opportunity for spiritual growth plan, using celebrative religious coping where the individual and God are active partners in coping) are tied to better outcomes for the individual (e.g., higher self-reported self-esteem, better psychological adjustment). Whereas some forms of religious coping (e.g., expression of religious discontent with God or congregation) are associated with worse outcomes such as poorer mental health status and poorer resolution of the negative event (Pargament, 1997; Weber & Pargament, 2014).

Religious coping in mental health – theories and research

A study by Koenig, George, & Peterson (1998), examined the association between intrinsic religiosity and remission of depression among 94 depressed medically ill men (aged 60 years or older) who had been admitted to medical inpatient services at a university medical centre. Intrinsic religiosity was found to be significantly associated with a greater probability of remission and a more rapid remission from depression, but church attendance and private religious activities were not.

Maltby & Day (2003), have expanded upon this finding in relation to different aspects of religion. They argue that individuals have one of three primary religious orientations; intrinsic, extrinsic, or quest orientation. Intrinsic religion refers to the self-motivated practice of religion, thus people with intrinsic orientation are totally committed to their religion beliefs and it plays a routine and dynamic role in their everyday life, informing and guiding the individual's thoughts, actions, and feelings. In contrast, extrinsic religious orientation refers to the practice of religion that has an external motive (e.g. going to church in the hope it will improve one's social status or to gain feelings of protection or consolation). Quest orientation refers to individuals who are marked by their desire for growth and constant search for answers in life. According to Batson, Schoenrade, & Ventis (1993), the quest orientation is a way of thinking that involves a willingness to actively confront and struggle with tough issues, an open and flexible approach to learning, a skeptical and doubting attitude toward simple solutions and answers to difficult problems, and a complex highly differentiated framework for viewing the world (Batson et al., 1993). This might help us to better understand Koenig et al's

study and why intrinsic religious practice was associated with better and faster remission from depression but extrinsic activities, such as church attendance, were not. However, this does not explain the lack of an association with private religious activities which would appear to be reflective of intrinsic religious orientation, and warrants further research.

Koenig, Ford, George, Blazer & Keith (1993), also found that religious involvement was associated with less anxiety. Attendance at religious services, self-rated importance of religion, private religious activities were correlated with recent and life time anxiety disorders among nearly 3000 adults. Interestingly, religious involvement was found to be associated with decreased recent and lifetime anxiety among the youngest patients (aged 18-39 years), but not among the oldest (aged 60-79 years) when gender, chronic illnesses, negative life events and socioeconomic status were controlled for.

The above examples provide some evidence of a positive correlation between increased religiosity and better mental health outcomes. Other research has reported substantial positive associations between religious involvement and a variety of health outcomes. For example, attendance at religious services was shown to be strongly related to physical health, mental health, and mortality in community-based samples (Ellison, 1995; Koenig, George, Hays, Larson, Cohen & Blazer, 1998; Koenig, Hays, Larson, George, Cohen, McCullough, Meador & Blazer, 1999). Those who attend religious services once a week or more were found to have fewer illnesses, recover more quickly from illnesses, and live longer when compared to individuals who attended less frequently. Further studies of clinically-based samples on illness development and

outcomes reported that religious coping was found to be the most powerful predictor of recovery and survival (Oxman, Freeman, & Manheimer, 1995; Pargament, 1997).

People who reported relying on their religion to help them to cope with illness tended to recover more quickly from illness and maintained a better tolerance to invasive medical procedures such as coronary bypass surgery (Oxman et al., 1995).

Evidence has suggested that there are positive outcomes between religion and physical health, and mental health (McCullough, Hoyt, Larson, Koenig, & Thoresen, 2000). A number of studies reported that religion and spirituality are positively related to physical and psychological health. For example, religious involvement has been associated with decreased mortality rates (Koenig, Hays, Larson, George, Cohen & Blazer, 1999) and fewer depressive symptoms and higher positive affect (Patrick & Kinney, 2003). In addition, religious commitment or religious involvement can have a protective role that lessens the impact of adverse interpersonal life events and social adversity on physical and mental health. It might also help these people to cope effectively with illness when compared with individuals without such beliefs (Matthews, McCullough, Larson, Koenig, Swyers, & Milano, 1998; Krause, 1998).

In addition, religious coping has been linked with the health and related mental health outcomes of a wide variety of critical life situations, such as illness (Koenig, George, & Peterson, 1998; Tix & Frazier, 1998; Trevino, Pargament, Cotton et al., 2010), war (Pargament, 1997), and the death of a loved one (McIntosh, Silver, & Wortman, 1993).

As a result, interest in research on religious coping with major life events and its implications for health has been growing increasingly (Abu-Raiya & Pargament, 2015). For example, psychologists have investigated many religious variables (e.g., religious beliefs, practices, motivations, conversion and attachment to God) and their associated links to indices of physical and mental health with promising results (see Paloutzian & Park, 2013). In addition, studies on religious and spiritual coping have covered various populations and different life stressors (e.g., physical illness, childhood trauma, bereavement, divorce, and natural or man-made disasters), all of which begin to shed light on how people utilised and benefited from religion in coping with life stressors and traumatic events (Gall & Guirguis-Younger, 2013).

In summary, several studies have shown that religion offers different coping methods which can help people to manage difficult and stressful situations. However, it is important to acknowledge that religion can also be a source of negative and harmful coping (e.g., discontentment or anger with God, clergy, or congregation) all of which can be associated with impaired mental health which in turn results in poorer resolution of negative life events (Pargament, 1997).

Negative religious coping activities indicate an ominous view of the world and a religious struggle (i.e., negative religious coping) to find, conserve and maintain significance in life. Such struggles or negative coping are reflective of conflict, question, and doubt regarding matters of faith, God, and religious relationships (McConnell, Pargament, Ellison & Flannelly, 2006). Whereas positive religious coping has been linked to better health and well-being, negative religious coping methods have been linked to greater depression, fatigue, and pain among cancer patients (Cole, 2005;

Sherman, Simonton, Latif, Spohn & Tricot, 2005) as well as higher depression, anxiety, and obsessive-compulsive behaviors in an American national survey (McConnell et al., 2006).

From the above, it can be concluded that many empirical studies have illustrated that positive religious coping can be positively associated with desirable physical and mental health indicators, whereas negative religious coping is positively linked to and connected with undesirable physical and mental health indicators. However as yet, to date, the mechanisms by which religion becomes a positive or negative construct for individuals is rather poorly understood.

Religious coping is a multidimensional process involving ideological, intellectual, ritualistic, experiential, and consequential dimensions (Spilka, Hood, & Gorsuch, 1985). These aspects are argued to serve people in the search for meaning in a variety of stressful life situations; thereby providing a sense of meaning and purpose, emotional comfort, personal control, intimacy with others, physical health, or spirituality (Pargament, 1997). According to Pargament (1997, p. 92), "*the significance [of religion] is, in part, a phenomenological construct involving feelings and beliefs associated with warmth, importance, and value. It embodies the experience of caring, attraction, or attachment*". These significant values or what people care for and are attached to could be in a variety of different domains, such as; material (e.g., money, food, cars, house, or drugs), physical (e.g., health, fitness, or appearance), psychological (e.g., comfort, meaning, growth), social (e.g., intimacy, social justice, community), events and transition (e.g., birth, death), and/or spiritual (e.g., closeness with God, religious experience) (Pargament, 1997; Pargament, 2002).

In the face of stressful life events, an individual's religious beliefs and practices have to be transformed into specific forms of coping and these specific coping methods seem to have direct effects on the individual's health during stressful times (Pargament, 1997). That is to say, the two reasons underlying the motive of accessing religion in the coping process are its possible availability as part of the orienting system and its possible availability as a compelling way of coping (Pargament, 1997). Hood, Hill & Spilka (2009) noted that when people confront a crisis or stressful situations they generally depend on a system of beliefs, practices, and relationships where all of these orienting techniques have an impact on the way that they reflect on and deal with their difficulties. Thus, in the process of coping people will translate this general orienting system into specific appraisals, goals, and related practices all of which will help them to find a way to deal with the difficulties and come to terms with life's events (Pargament, 1997; Hood, Hill, & Spilka, 2009). Within each of these orientations (intrinsic, extrinsic, or the quest) people can use either positive or negative religious coping styles.

It is important to take into consideration that these behaviours are formed and shaped by the individual's culture and experience (Klinger, 1977; Pargament, 1997). People will generally cope using the tools that are most available to them. Hence, religion is a more accessible tool for individuals for whom religious beliefs, feelings, practices, and relationships are a part of their usual orienting system. These people are most likely to translate their religious commitment into action in particular situations. In other words, the more religion is embedded and rooted in the guiding framework for living, the more quickly and easily it can be accessed in coping process.

The religious coping literature suggests that people are more likely to see God and their congregation as loving and supportive than a source of painful and punishing associations (Bearon & Koenig, 1990). Nevertheless, the ineffective side of religious coping does warrant more careful attention.

Religious coping amongst parents of children with disabilities

Tarakeshwar & Pargament (2001) assessed the role of religion in the coping process of families of children with autism and found that positive religious coping was associated with better religious outcomes (e.g., changes in closeness to God/church and spiritual growth), while negative religious coping was related to greater depressive affect and poorer religious outcomes. Therefore, religion appeared to act as a protective or defensive system that motivated efforts by family members to cope constructively with the crisis of illnesses (Spilka, Hood, & Gorsuch, 1985).

Similarly, Haworth, Hill, & Glidden (1996), measured the religiousness of parents of children with developmental disabilities and found that some mothers do indeed gain strength and support from using religion as a coping mechanism. For example, some mothers used religion to explain the reason behind their child's handicap (e.g. "it's God holly will," "she is the way God made her," "truly a blessing from God," "it was in God's plan.")

While the behavioural problems associated with ASD increased parental stress, researchers (Gray, 2001; Divan et al., 2012) found that parents of children with ASD could cope with these challenges by applying some strategies, which include acceptance of the biological basis for ASD known as "*accommodation*", "*resistance*" to

biological basis, and “*transcendence*” (e.g., using a spiritual pathway to understand their situation). The transcendental path, is when parents draw on their religious faith as a way to make sense out of their children’s suffering (Gray, 2001; Divan et al., 2012). Therefore, spiritual or religious involvement may mitigate the adverse and harmful effects of these experiences (Koenig, McCullough, & Larson, 2001), as well as providing an important framework to help parents explain and interpret disability (Jegatheesan, Miller & Fowler, 2010). Thus, religion across different cultural groups has been found to help families emotionally and socially as it plays a large role in parents’ coping abilities, although this will vary depending on individual families (Dyches, Wilder, Sudweeks, Obiakor & Algozzine, 2004; Skinner, Correa, Skinner & Bailey, 2001).

Consequently, when faced with a difficult challenge, people and families used religion as a coping mechanism (Pargament, 1997). According to Pargament (1997), the five main functions of religion are: meaning, control, comfort and spirituality, intimacy and spirituality, and life transformation (Pargament, Koenig & Perez, 2000). So, when individuals face challenges, they may use religion as a framework from which to search for meaning. This meaning will aid with understanding and interpretation of any future possible changes that the person may need to make to adapt and adjust to the stressor. Although people may comprehend the challenge, they may feel that they have no control over the unfolding of events. Therefore, various religious practices such as prayer and certain rituals help people to achieve a sense of control during stressful events (Pargament et al., 2000).

In summary, it has been demonstrated that the influence of religion lies in its multifunctional nature and its ability to provide various methods of coping for diverse

situations. However, better understanding the ways in which individuals draw upon religion in order to understand and deal with stressors is paramount for comprehending how these religious coping methods facilitate the connections between the individual's general religious orientation and the outcomes of major life events.

Limitations in the current literature about religious coping

Tarakeshwar & Pargament (2001), have pointed out that the role of religion as a coping process in confronting the stressors of raising children with disabilities, including children with ASD, and its outcomes on families, has been largely overlooked, with only a few studies examining this to date. In addition, the existing literature on coping by parents of children with autism is very limited and leaves many unresolved issues, with most of the research based mainly on the stress and coping model of Lazarus & Folkman (1984) (Benson, 2010). Researchers have generally grouped coping methods into two general types, *problem-focus* coping and *emotional-focus* coping (Benson, 2010).

Furthermore, most studies when researching the connection between religion and psychological adjustment, have examined religion from a general perspective, using basic and single item measures that would typically oversimplify religion's role in the coping process during stressful events, and which can therefore say little about the way in which it functions in such situations (Ano & Vasconcelles, 2005). For example, (McIntosh, Silver & Wortman, 1993) measured religious importance with a single item and examined its role among 124 parents coping with an infant's death. Their results indicated that the importance of religion was connected to the mother's well-being, but

this does not enable us to understand exactly what it was about the nature of the religious coping nor exactly how it impacted upon the mother's wellbeing.

Another study examined the organisational aspects of religion and psychological adjustment to stress and reported that greater frequencies of church attendance were associated with lower levels of depression in a sample of 96 male inmates aged over 50 (Koenig, 1995). However, again, this study does not elucidate the processes by which church attendance impacted on depression.

Finally, a further study examined the relationship of religious affiliation (measured by a single item asking respondents whether or not they identified with any specific religious affiliation) to quality of life among 40 individuals with HIV (Flannelly and Inouye, 2001). The authors found that religious affiliation was positively related to quality of life but again their single item measure of religion did not allow for further exploration of how religion mediated experiencing HIV and quality of life.

These studies present interesting findings, but do not go far enough to enable us to understand *how* religious coping impacts on quality of life of mental or physical health outcomes. More importantly, most of the above studies have focused on Christian samples and have been conducted in the West. As such, their findings cannot be generalised to individuals in other cultures or of other faiths.

While such studies demonstrate a potentially interesting relationship between religion and mental health and attest to the importance of religion for people managing stressful events, such a global index of religious involvement (e.g. importance of religious belief, frequency of church attendance, frequency of prayers, religiosity,

denominational affiliation,...etc.) explains very little about the particular religious coping strategies that have been employed by people when dealing with life stressors (Pargament, 1997; Ano & Vasconcelles, 2005). Examining religion from a general dispositional perspective only demonstrates religious involvement whereas the focus of religious coping concentrates on ways people turn to religion and utilise it in difficult situations (Pargament, 1997).

In short, these studies indicate religion's effectiveness in people's lives but do not explain the nature of its role in the coping process or the way it functions, serves, and is used during a crisis. Pargament, Koenig, & Perez (2000) state, "it is not enough to know that an individual prays, attends church, or watches religious television. Measures of religious coping should specify how the individual is making use of religion to understand and deal with stressors" (p. 521).

Studies Which Explored the Role of Religion in Families of children with Autism/special needs

To date, only a few studies have explored the role of religion in parenting a child with special needs and the results demonstrate two themes; religion can function as a supportive and a positive resource for those families or act ineffectively with negative outcomes. Religion reportedly helped families to accept their difficulties as a gift from God (Skinner, Bailey, Correa & Rodriguez, 1999), and was seen as an opportunity for families to become closer and attain higher spiritual levels (Skinner et al., 1999). In addition, religion played a powerful role in explaining the misfortunes and suffering of these parents (e.g., the child was given by God for a reason) (Weisner, Beizer, &

Stolze, 1991), and gave hope, strength, and patience (Pargament, 1979; Tarakeshwar & Pargament, 2001).

Negative outcomes were that religion, reportedly, affected the lives of these parents by viewing God as unhelpful in parenting their child with disabilities. Religious experiences were perceived as aversive to the coping process, and feelings of punishment or having doubts about the benevolence of God (Rogers-Dulan, 1998).

The spiritual and religious paradigm of parents with disabled children was seen in these studies to have strongly affected the parents' appraisal/evaluation of children with disabilities. As a result, researchers noted that members of various cultures may appraise the stressor of autism differently, be it negative or positive appraisal (Dyches, Wilder, Sudweeks, Obiakor & Algozzine, 2004). There are people who believe that intellectual or developmental disability is a punishment for the sins of the parents (Skinner, Bailey, Correa & Rodriguez, 1999), whereas, others accept the child as a blessing or gift from God, feeling that they have been found worthy of such a child or they have been given such a challenge to become a better person. However, in the later example the religious and spiritual paradigm of these mothers was heavily influenced by Catholicism, which may have strongly affected their appraisal of their disabled children (Skinner et al., 1999). From the above, two beliefs commonly existed in regard to individuals with disabilities, where some societies may believe it is a result of negative factors such as sins or curses, other societies view such individuals as a blessing or a special gift from God (Jegatheesan et al., 2010; Pitten, 2008).

According to Al-Mosa (1999), Saudi society may perceive disability as a punishment from *Allah* God, because one of the parents was disrespectful toward a family with a child with a disability, or the disability might be considered as a test from *Allah*, and the patience of those who are tested will not go unrewarded by Allah, who has prepared a much better place for the parents in heaven. These previous conclusions are based on the Islamic faith and follows the Quran and the Sunnah as stated by the Prophet Muhammad, which is what all Saudi Muslims strictly adhere to following. In addition, Saudi people, in general, base their cultural values and management of disabilities in particular from the teaching explained in the Quran and from the Sunnah (Al-Mosa, 1999; Al-Aoufi, Al-Zyoud & Shahminan, 2012).

To date, only two studies have been found which directly address the role of religion as coping resource in parents of children with autism. These are “Religious Coping in Families of Children with Autism” (Tarakeshwar & Pargament, 2001), and “Religiosity, Spirituality, and Socio-emotional Functioning in Mothers of Children with Autism” (Ekas, Whitman, & Shivers, 2009). Only one further study has investigated how parents of children with autism in Saudi Arabia understood and reviewed the cause of their child’s disorder “Understanding autism in Saudi Arabia: a qualitative analysis of the community and cultural context” by (Alqahtani, 2012). I will consider each of these studies, in turn.

Summaries of the Three Studies

1. Religious coping in families of children with autism (Tarakeshwar & Pargament, 2001)

In this study, religious coping methods were assessed amongst 45 participants; mothers from Caucasian families of varying marital status of autistic children and examined in association with psychological adjustment, stress-related growth and religious outcome.

Positive and negative aspects of religious coping methods towards autism were identified. Both approaches provided insight into the development of strategies for supporting parents of autistic children and the children themselves. However, the conceptual basis of religious coping in this study was based on a Western and universal notion of religion, whereas it may be the case that different religious beliefs entailed different types and degrees of coping.

2. Religiosity, spirituality, and socioemotional functioning in mothers of children with autism spectrum disorder (Ekas, Whitman, & Shivers, 2009)

This study examined three dimensions of religiosity in the socio-emotional functioning of 119 mothers of children with ASD. Religious beliefs, religious activities, and spirituality were included in addition to a wide range of outcome variables, including stress, depression, self-esteem, life satisfaction, positive affect, and sense of control. The primary goal was to investigate the specific factors that may serve to directly reduce the negative psychological effects of raising a child with ASD.

The authors found that positive outcomes were associated with religiousness and spirituality and, to a lesser extent, lower levels of negative outcomes. Of the two predictors, spirituality accounted for more unique variance in positive outcomes. In contrast, religious activities were related to more negative outcomes and lower levels of positive outcomes. Higher scores on the religious beliefs and spirituality measures were associated with higher self-esteem, life satisfaction, positive life events, positive affect, psychological well-being, optimism, and internal locus of control.

The sample in this study consisted of mainly Caucasian, upper middle-class families. From the analysis, it is not possible to determine whether the benefits of religious and spiritual beliefs were short-term or long-term or whether different religions and spiritual orientations influenced the outcome. In addition, there were no separate measures of religiosity, which could disentangle the effects of the different types of supernatural and religious beliefs and different types of religious practices. There was not any focus on shared similar, or competing, religious beliefs and practices between fathers and mothers, which might influence family functioning.

3. Understanding autism in Saudi Arabia: A qualitative analysis of the community and cultural context (Alqahtani, 2012)

This study is the only known qualitative study in this area, to date. In this study the authors qualitatively investigated how 47 parents of children with autism in Saudi understood and viewed the causes of their child's disorder using semi-structured interviews.

The findings of the study indicated that parents held many misconceptions about the cause of autism. The most frequently identified causes for autism was medical causes (e.g., medical investigations during pregnancy and infant vaccinations), mother's health wellbeing (e.g., vitamin B deficiency, being unable to breast feed and lack of time for emotional interaction with the child) and culture, religious and magic causes (e.g., evil eye and black magic). Parents' practices in regard to treatments for their child included the following; religious activities, which was the most frequent (reading the Quran, seeking help from religious healers), returning to religious help when the doctors had failed to heal the child, dietary treatment, which was reported to be used by more than half of the parents or had been used previously, and finally, hyperbaric oxygen therapy which had been used by some parents following advertisements on TV.

Alqahtani (2012) highlighted how the prevalence of (cultural beliefs) around autism could reflect parents not receiving the answers/solutions that they felt they needed from medical doctors. Also, he noticed that genetic causes were not mentioned in any of the interviews. He explained that, it is not possible to know whether this reflects the doctors' lack of explanation, or is due to a more culturally-bound situation, in that parents themselves need to be seen in an ideal genetic state, otherwise, any genetic abnormality in the child would stigmatise the parents and the family as the cause of the problem. This would have further repercussions for the other siblings, particularly daughters, with respect to how desirable potential marriages would be with other families. In addition, there was a clear absence of the educational, behavioural or developmental therapies commonly used in other countries. The author argued that the results highlight the need to improve medical education in Saudi.

This study provides a brief, but helpful insight into how parents in Saudi understand the causes of their child's Autism. However, it would have been helpful if the interviews included questions concerning how parents developed their beliefs and where they gathered their knowledge about autism from.

The author concluded that the results of their study highlighted a need for improved medical education in relation to autism. However, as the author had no information concerning where/how parents developed their understanding of autism, it cannot be assumed that a lack of appropriate education for medical staff is the cause.

The authors also conclude that their study supports the use of educational interventions. Again, it was not based on the data that had been gathered in this particular study. While there is evidence for the use of educational interventions (some of which was mentioned in the study), this was not what the interviews, and therefore subsequent data, were about. The interview data were interesting in that they highlighted a lack of these therapies in use in Saudi. This in itself is important to understand, and it would have been useful if the authors had explored this further, rather than using it as an automatic justification for the need of more educational therapies. It could be, for example, that the therapies are known of, and disliked, rather than them simply not existing, but it is not possible to know this from the data they presented.

It was interesting that parents often followed medical help to start with, then returned to more religious ways of coping with 'healing' their child, as they felt the medical treatments did not work, which might reflect a lack of understanding about

autism, in terms of expecting a 'cure'. Doctors perhaps need to be clearer and more skilled in managing parents' expectations of what the available therapies could offer.

The main problem encountered by the author during the interviews was that he did not interview mothers alone. The author's explanation for such was based on religious and cultural rules, where it is forbidden for men to interview women alone, even for the purpose of collecting research data. Therefore, interviews must be conducted by a female interviewer or by a male interviewer on condition that one of the mother's relatives attends. However, this was not explored in extensive depth in this study. The author did not explain how such a cultural rule affected collecting the data, nor how the accompaniment of a male relative impacted mothers' answers. In addition, in Saudi it is culturally known that mothers are fully and solely responsible for taking care of their children, including the child with autism, which means that fathers sometimes would not be aware of some of the information required. It was not clear how this was dealt with. For example if the father was present during the interview or if the father was interviewed solely.

Finally, the translation of the interview data did appear sometimes inadequate, which will have potentially affected the quality and the validity of the data. It is important to have a native English speaker review any comments that were translated from original language.

Summary and research aims

From the above, it can be concluded that little research exists about family adaptation to autism and that most of the research that does exist originates from

Western cultural perspectives and religions (Dyches et al, 2004). What research there is has tended to use quantitative and simplistic, unidimensional measures of religion which does not allow for a more in depth understanding of the relationship between religious coping and positive and negative outcomes to physical and mental health crises and stressful life events.

Research on autism in general is very scarce in the Gulf region with very little attention paid to people's own personal experiences. Still less research has explored religion as a coping strategy, despite the centrality of religion to every aspect of life in this context.

Finally, a further deficit in the current research on parental coping with children with autism has been to explore mothers' specific experiences and beliefs, given they are, in nearly every society, most likely to take on the burden of most care-giving responsibilities. This is compounded when we consider the lack of voice that women and mothers have in Muslim societies, such as Saudi Arabia.

The aim of this study was, therefore, to explore the experiences and religious coping of mothers of children with ASD in Saudi Arabia. My intention was to do this via ethnography and in-depth qualitative interviews with mothers in order to develop a richer and more in-depth understanding of their experiences and how their perspective informs and impacts their coping. Specifically, this study aimed to explore Saudi mothers' faith and to try to understand how their faith influences their coping and understanding of their children with autism.

Chapter 2: Social and political context of the study

In this Chapter, I outline the geopolitical, sociocultural and gender context in which I carried out my research. I first describe this with reference to the Kingdom of Saudi Arabia, before describing the cultural and service context for people living with disability, and with Autistic Spectrum Disorder in particular, in Saudi Arabia.

Geopolitical setting

I carried out this study in Riyadh, Saudi Arabia. The Kingdom of Saudi Arabia (KSA), is the largest country in the Arabian Peninsula with an estimated population of 32.5 million, of whom 20.8 million are Saudi nationals (General Authority for Statistics, 2019). Riyadh is the capital and the largest city in the Kingdom, where Arabic is the spoken language. Saudi Arabia (SA) is the place of the two holiest cities of Islam: Makkah (Mecca) and Madinah (Medina). Makkah is located at the heart of the Kingdom, is the birthplace of Islam and the centre to which all the world's Muslims turn to prayer every day (The Ministry of Education (MOE), 2019).

The Kingdom of SA is a fully sovereign Arab state, where Islam is its religion and its constitution is based on the Book of God (Quran) and the Sunnah (Traditions) of His Messenger Prophet Muhammed, may Allah's blessings and peace be upon him (PBUH) (MOE, 2019; The Shura Council, 2019). KSA is a Monarchy with a Council of Ministers and the Shura Council (Consultative Council) (The Shura Council, 2019). The King heads the Government and the Council of Ministers, which respectively are the executive and administrative bodies in the country.

Social and cultural context

Islamic religion shapes the country's social and cultural beliefs (AL Yousef, 2016). For example, religious education (i.e., Islamic education) is accentuated throughout the school system and university (Jamjoom, 2010).

Saudi society is conservative and tribal. Each family belongs to a tribe or bigger family, and is considered to fall under its authority. No matter how far apart a family lives, its members are expected to maintain their loyalty to the tribe (Determann, 2013). There are dozens of separate tribes, which differ in their size and power. Tribal members often consider their families to be the most powerful authority over their lives. Surnames denote tribal membership and communicate a tribal identity.

Most Arabic societies are collective and authoritarian, in which the family (extended or nuclear) is more important than the individual (Dwairy, 1997, 2002). Self-esteem in Arabic individuals may be particularly linked to the collective identity, and family approval, identity and affiliation (Dwairy, Achoui, Abouserie & Farah, 2006). The extended family system is predominant in Saudi society and is still the norm, although it is decreasing due to the changes in society and the workplace. Even when some members of the family move out and live in their own households, a great deal of the extended family rules are transferred and followed. Cultural rules, social standards and Islamic Laws are strongly present and paint all aspects of Saudi life.

The gender context

The Saudi education system is separated by gender from elementary age to university level (Salloom, 1995). Such a system also applies to all schools and centers for people with disabilities, including autism.

These issues pervade the practice of conducting research within such settings, and extend beyond geographical boundaries. For example, in a recent study by AL Yousef (2016), which partly took place in the UK, she reported that these issues were present when arranging focus groups for Saudi men and women together even in a UK University campus setting, with female and male students refusing to join the proposed mixed gender focus group.

Gender segregation and the separate education of men and women in particular is central to my research and most research in SA. Gender segregation in Saudi stems from a conservative society that has always maintained very strict traditions of segregation between men and women in social gatherings and in all workplaces. Gender separation can be found in many sectors which includes schools, universities, government departments, and some public places. Such rules including traditional dress and the existence of clear gender segregation are what sets the difference between Saudi Arabia and other nations (Abadeer, 2015). These rules are kept and maintained by the Committee for the Promotion of Virtue and the Prevention of Vice (CPVPV), also known as the religious police. All women must comply with the conservative dress code which was laid down by the king's advisory body, the Shura Council (Alariefy, 2016). Traditions also govern the outdoor costumes for men and

women. Women have to wear black cloaks (Abaya) in Saudi society and men white vestment (*Thawb*) and a head cover (*Shemagh*). The revealing and exposure of women to men is actively prohibited by the Law of Islam (Sharia) (Binbaz, 2019).

Women in the kingdom are also not allowed to move about in society without a male guardian regardless of their age (Alariefy, 2016). Women would need to *get permission from my husband, my father or my brother* for many activities, including participating in research. Additionally, Saudi law requires women to obtain written permission from a male mahram (guardian) for different activities such as; marriage, education, traveling abroad, passport renewal, accepting a scholarship to study abroad, and to obtain health care (Wynbrandt, 2010; AL Yousef, 2016).

While boys become independent at the age of eighteen, women of all ages have to be under the guardianship of a man (e.g., her father, brother, husband or even an adult son) who would have a say in most women's activities (Abadeer, 2015). Parents set their own degree of strictness, which usually stems from their own extended family, aligning their smaller family with what are the norms and expectation within the extended family provided its members with protection, support strength and acceptance.

Another aspect of gender inequality relevant to this study and a prominent social issue is that women in SA are forbidden to drive. This limits and restricts female researchers, female participants, and all women from moving around easily, especially as there is no public transportation system.

As well as having restrictions placed upon their movements, women in SA are also limited in their capacity to make decisions. This plays out in every area of life, and

research is no exception to this. For example, in his qualitative paper, Alqahtani (2012), a male Consultant Clinical Psychologist stated that interviewing mothers of children with autism in the hospital without their male guardian or relative present, even for the purpose of collecting research data, was a significant barrier in his research. He related this to the cultural rules of SA which forbid men to interview women and vice versa. So, for Alqahtani to conduct his research, a female colleague had to be recruited to speak directly to the mothers. Most Saudis keenly adhere and implement Sharia Law into their daily lives, so it is both a religious concern and a cultural value which all Saudis grow up with, study, embrace, and practice with varying strictness.

These examples clearly illustrate another component of Saudi society that is of male domination and the overall social constraints on women. In addition, all segments of Saudi society continue to be enmeshed between religion and traditional grounds that makes navigating such terrain rather tricky and difficult for both the 'insider' and 'outsider' researcher. Clearly, cultural issues (i.e., religious and cultural values with social standards) in KSA play a highly significant role in the country and will continue to do so. Saudi people also conform to them and implement them with variations in all of their lives' activities, as a result they needed to be deeply considered and understood before starting any research to minimize potential conflicts and setbacks.

Disability and autism spectrum disorder (ASD) in SA: the Socio-cultural Context

In Islam it is argued that individuals who have disabilities or special educational needs (SEN) should be treated the same as other members of society, that they have

rights and society has responsibilities and duties towards them. Islam also provides vivid examples of equality in the Quran and Sunnah (Al-Aoufi, Al-Zyoud & Shahminan, 2012). The most well-known example in the Quran tells of Allah reproaching his prophet Muhammad, because of how he treated a blind man. Allah's reprimanding of his prophet could be still read from the Quran today in Surat *Abasa*. *Abasa* is the 80th *surah* (is the term for chapter of the Quran) with 42 *ayah* (verse is one of the statement of varying length that make up the chapters *surah*). The *surah* is so designated after the word "abasa" and with which it opens:

-1- The Prophet frowned and turned away -2- Because there came to him the blind man, [interrupting] -3- But what would make you perceive, [O Muhammad], that perhaps he might be purified -4- Or be reminded and the remembrance would benefit him? -5- As for he who thinks himself without need, -6- To him you give attention. -7- And not upon you [is any blame] if he will not be purified -8- But as for he who came to you striving [for knowledge] -9- While he fears [Allah], -10- From him you are distracted -11- No! Indeed, these verses are a reminder.

In reality, however, cultural and local practices may seem to contradict this Islamic perspective. According to Al-Mosa (2010), the cultural constructs around SEN and disabled people in KSA is such that individuals should be treated with integrity, viewed compassionately, and accepted as members of the society who have substantial limitations but are nevertheless worthy of dignified treatment and respect. However, Al-Mosa then goes on to identify cases in Saudi where parents of normal developing children would not like their children to be in a mainstream school which accepts children with SEN. Also, Alariefy (2016) identified parents of SEN children who either hide their children from the public eye or provide a different account of the diagnosis to the outside world due to the cultural shame and stigma towards such children.

A number of Saudi's researchers have acknowledged similar observations where cultural practices negate Islamic perspectives (Alquraini, 2011; Alhudaithi, 2015). According to Kadi (2018), attitudes that disabled people are completely helpless, reliant on others, have little right to live or participate in society, are inevitably homebound, and have a low quality of life remain commonplace in Saudi society (Al-Gain and Al-Abdulwahab, 2002). These cultural attitudes are pervasive, and likely to influence societal, individual and family beliefs about disability in general and autism in particular (Ennis-Cole et al., 2013).

Introduction to Mental Health Services in the Arab Countries

Mental health practice in Arab countries has been described by Al-Krenawi (2005) as a broad and complicated topic due to the diversity between Arab populations. The various ways in which each country approaches mental health issues, the lack of awareness of mental health problems, the serious deficiency of mental health services, and finally the lack of appropriately qualified professionals are all issues even in the high income Arab countries. Furthermore, the lack of reliable epidemiological psychiatric baseline data in the Arab region is another major obstacle against providing reasonable planning for future psychiatric services, education, and research (Okasha & Maj, 2001). Okasha & Karam (1998), investigated mental health research in the Arab region and found that there was a lack of strategic and policy oriented research funding for all academic research. These factors hinder the development of research in Arab countries.

Another fundamental reason affecting the delivery of appropriate mental health care in Arab countries is that traditional healers are highly valued and often favoured over general health providers (Okasha, 2003; Al-Krenawi, Graham, Dean, Eltaiba, 2004). The importance of the traditional healers results from their close connection with the community and their claim to deal with the “mystical”, the “supernatural”, and the “unknown” (Okasha & Karam, 1998). As cultural beliefs about spirit possession, sorcery or the “evil eye” strongly influence how people interpret mental health symptoms, the first resort for the Arab families of mentally ill patients would be the traditional healer rather than the medical professionals (Okasha, Karam & Okasha, 2012). Thus, in this context, the reliance upon a deity and religious leaders in the Arab region is considered another common theme in coping with mental health issues (Al-Krenawi, 2005). In a study by Al-Krenawi, Graham, Dean, & Eltaiba (2004), conducted among young Muslim Arab females in Jordan, the United Arab Emirates (UAE), and Israel, the authors found that the rate of reliance upon religious doctrines to understand the causes and possible solutions to mental health problems was high (e.g., regardless of their nationalities, high proportions of respondents referred to God through prayer during times of psychological distress).

In Arab countries, therefore, traditional healers constitute an informal health care system, which cannot be overlooked (Okasha & Karam, 1998; El-Islam, 2008). In Saudi Arabia, up till the early 1980’s, religious faith healers were involved in the treatment of those with mental illness, especially those suffering chronic psychotic disorders and those who live in rural areas. To a large degree, such a practice still actively occurs everywhere in the KSA (Koenig, Al Zaben et al., 2014). In addition, religious faith

healing extends to exorcising demons or to countering the evil eye, jealousy, and magical forces which are thought to be responsible for the illness (Al-Habeeb, 2003; Koenig et al., 2014). Furthermore, research on mental illness from the Gulf Cooperation Council (GCC) countries suggested that sociocultural factors influence people's experience of mental illness in the region (Hickey, Prymachuk & Waterman, 2016). Thus, causal attribution of mental illness to demons (Jinn) habitually prompted people to seek help from traditional and religious healers (El-Islam, 2008). A study conducted by Al-Solaim and Loewenthal (2011) in Saudi demonstrated that psychiatric services seem to be seen as a last resort when other options (e.g. faith healers) are not successful.

Generally, in the majority of Arab countries there is no interaction between traditional healers and the medical profession (Okasha, Karam & Okasha, 2012). However, in Saudi Arabia, they have been officially constituted as part of the therapeutic staff team, with integrated indigenous healing practices in the modern mental health system such as using religious texts and recitation in management (Aloud, 2004; Okasha, Karam, & Okasha, 2012). These findings are consistent with a study conducted on Arab patients that pointed to a belief that only traditional or religious therapy (e.g. daily prayer or other religious rituals) could be used to treat mental illness (Al-Subaie & Alhamed, 2000). It is important to take into consideration the fact that around 70-80% of psychiatric patients in developing countries tend to express their emotions and feelings physically (somatization) and, in turn, this protects them from the stigmatization of being diagnosed with mental health illnesses and instead will lead the patient to consult a traditional healer or general practitioner rather than a psychiatrist (Okasha & Karam, 1998). Furthermore, in Qatar and Kuwait, patients' embarrassing,

aggressive, and destructive abnormal behaviours bring “social shame” not only to the patient but also to his/her family who are at the receiving end to this process (El-Islam, 2008).

In summary, traditional healers do and will continue to provide some form of intervention in the lives of mentally ill patients and their families, particularly where mental health services are not available for a community to access (Okasha & Karam, 1998). Additionally, their relationship with professional psychiatrists in the Arab communities can vary from full integration into the system to the total rejection of psychiatrists working with varying positions of collaboration and intervention as in most traditional cultures (El-Islam, 2008).

Specifically, an overview of the literature in relation to mental illness in the Kingdom of Saudi Arabia (KSA) has indicated a lack of an accurate estimate for the prevalence of such problems among the Saudi population (Almutairi, 2015), and despite the huge efforts and changes in KSA’s mental health care over the past 30 years, no studies to date have examined the prevalence of mental disorders in the Saudi community. Recent plans to conduct such a survey have been acknowledged between different agencies and the Saudi government (Koenig, Al Zaben, Sehlo, Khalifa, Al Ahwal, Qureshi & Al-Habeeb, 2014) but have yet to be conducted. Despite its immense oil wealth, Saudi people still faces enormous problems of access to mental health and services for psychiatric disorders as they are not well developed (Zeina, Al-Ayadhi & Bashir, 2014).

Due to the stigma of mental illness in Saudi, those who have the financial resources often prefer to consult private clinics and pay personally rather than going to government-funded general hospitals or psychiatric hospitals, where patients are seen for free and without the need for referral (Koenig et al., 2014). In Arabic societies as in most societies, including Western cultures, individuals with mental illness and their families are often stigmatized and isolated. Hence, shame can cause families to impose social isolation on a sick family member (Al-Krenawi & Graham, 2000). This is because in Saudi, the popular view is that mental illness is the punishment of Allah or inflicted by evil spirits, and this picture is similar in many Islamic countries where mental illness is still associated with evil spirits, effects of the evil eye, magic, and punishment from God, or associated with violence, addiction, and suicide (Pridmore & Pasha, 2004).

This external attribution of mental illness to supernatural forces (e.g. black magic, jinn, evil eye, evil spirit) that is particularly common among Gulf patients, can be argued to serve a protective function since certain symptoms will not be as stigmatized and may not create such strong feelings of guilt (El-Islam, 2008; Al-Solaim & Loewenthal, 2011). Largely, Saudi society still believes that even physical symptoms have supernatural causes and therefore seeking help from spiritual or traditional healers is still commonly practiced even among fairly well-educated people. For example, a study by Obeid, Abulaban, Al-Ghatani, Al-Malki & Al-Ghamdi (2012) explored perceptions of the causes of seizures in Saudi Arabia. These researchers from the neurology section of the department of medicine at King Khalid National Guard Hospital surveyed 398 university graduates school teachers and undergraduate students at two universities. When asked about the cause of epilepsy, 38% of teachers and 47% of students said it

was a psychiatric illness. Possession by jinn was reported by 40% of teachers and 50% of students to be the cause of epilepsy. Reading the Quran (*ruqya*) was considered a form of treatment by 68% of teachers and 82% of students. Cautery felt an acceptable treatment by 10% of teachers and 16% of students. In addition, for those who believed that possession by jinn was the cause of epilepsy, fewer indicated medication as a possible treatment, and more indicated that reading from the Quran could cure the condition. One should bear in mind that these responses represented well-educated individuals in the current generation.

In another example, a survey examined the attitudes and beliefs of hemodialysis patients (i.e. what they thought caused their kidney disease and the most important factor for their recovery) at a public hospital in Riyadh. They reported that in most cases (93%) patients said the cause of their illness was the will of God and only 1% said it was due to medical or physical causes, whilst 6% attributed other causes. Overall, 98% said that the will of God was the most important factor responsible for their recovery, and interestingly, no one said it was due to medical or physical treatment (Harakati, Shaheen, Tamim, Taher, Al Qublan & Al Sayyari, 2011). It can be concluded that behaviour, understanding and perception of illnesses are uniquely characterized by an individual's own culture and belief system. In this vein, the vast majority of the patients in Harakati et al., (2011) study did not believe in the biological basis of their illnesses, instead God's will was seen as the key factor. Muslims believe that cure cannot happen without God's wish, in keeping with the deep rooted Islamic belief that there is always hope in God's intervention in providing a cure for all illnesses. Thus, Muslims always

recite from the Quran *ayah* 80 from sura *Ash-Shu'araa*, "*Wa-itha maridtu fahuwayashfeen*" which translate to "*And when I am ill, it is He Who cures me*"

Although mental health services are expanding in the KSA, mental health care still also takes place within the nuclear and extended family, and such a matter is frequently kept a secret (Okasha & Karam, 1998; Koenig et al., 2014). Reasons such as changes in the demographics and lack of resources are given to justify the limitation of mental health services. Another possible explanation thought to be hindering provision for people with mental illness is the prevailing opinions shaping public attitude towards such a matter and people (Littlewood, 1998; Li, Logan, Yee & Ng, 1999). Attitudes are significant determinants of behaviours which in turn have a wide-ranging influence on society (AL-Adawi, AL-Naamani, AL-Maskari, Martin, AL-Riyami & AL-Hussain, 2000), as mental illness can often disenfranchise people, reduce their status and disempower them (Callaghan, Shan, Ching & Kwan, 1997).

Given the important impact of cultural and religious influence in Saudi, it is essential that mental health issues must be understood in this context and mental health care tailored and implemented in a way that is respectful of these long held sacred traditions and belief systems. The impact of these sensitive issues and concerns about mental health services is very serious and needs to be given full attention when planning and implementing the care for mentally ill individuals in the Arab region since they are very important parts of the effective coping techniques in that specific culture.

Overview of Special Education in Saudi Arabia

People with disabilities in Saudi Arabia were not able to obtain special education services until 1958. As a result, parents of children with disabilities were directly responsible for providing and assisting their children for all their educational needs (Al-Ajmi, 2006). According to Salloom (1995), special education services in Saudi Arabia started to emerge in 1958 when a group of blind students received their education in schools known as “Scientific Institutes”. By 1962, the Ministry of Education established the Special Learning Department to develop learning and rehabilitation services particularly for blind and deaf students as well as those students who were classed as “mentally retarded” (Afeafe, 2000). In short, the Ministry of Education in Saudi Arabia is responsible for providing free and appropriate education for all students, including students with disabilities (Alhudaithi, 2015).

Laws regarding people with disabilities in Saudi Arabia

A Legislation of Disability (LD) was passed in 1987 as the first law for people with disabilities in Saudi Arabia. The LD includes provisions to guarantee individuals with disabilities equal rights to those like everyone in society. The LD contains many articles that define disability, describe programs for prevention and intervention, procedures for assessment, and diagnosis to determine their eligibility for special education (Ministry of Health Care, 2010).

In 2000, the Saudi government passed a Disability Law to ensure that people with disabilities have access to free and appropriate medical, psychological, social,

education, and rehabilitation services through public agencies. In addition, this legislation requires these agencies to assist and help eligible people in many areas, such as, welfare, health, education, training and rehabilitation, employment, and other areas (Prince Salman Centre for Disability Research, 2010).

In conclusion, these policies and legislation have reinforced and supported the equal rights for individuals with disabilities in obtaining free and appropriate education. However, the reality of the current situation has shown that these laws have not been put into practice, even though they were passed nearly two decades ago. Therefore, a gap is created between the framework of these laws and the provision of services leaving many students with disabilities without special educational services (Alquraini, 2011). For example, according to the Ministry of Education in Saudi (2008), 96% of students with multiple and severe disabilities received their education in separate institutes in 2007-2008, and were not integrated with other able-bodied children.

Autism Spectrum Disorder (ASD) in Saudi Arabia

According to AL-Turaiki (1997), Saudi Arabia, in recent decades, has undergone a period of significant economic development, which has positively impacted on health care services and resulted in both a decrease in child mortality and greater numbers of disabled children surviving. In addition, the Saudi government is initiating further steps to increase public awareness of disabilities, as well as working towards the prevention of disabilities (Abouammoh, Al-Zahrani, Altwaijri, Tamim & Al-Twaijri, 2007).

It is difficult to describe the extent of ASD in Saudi Arabia for a variety of reasons. Firstly, there are inconsistencies in research on disability in general. There is

a lack of appropriate epidemiological research (Al-Gain & Al-Abdulwahab, 2002), and most of the data collected on disabilities has largely taken the form of surveys (Al-Gain & Al-Abdulwahab, 2002). In addition, most studies on disabilities in Saudi Arabia have not been published, they use various definitions of disability, or have been performed on single types of childhood disability (Shawky, Abalkhal & Soliman, 2002). Also, there is no standard outcome measure used to estimate or recognize the degree of disability, which results in a lack of validity when comparing results and published research in Saudi Arabia (Al-Gain & Al-Abdulwahab, 2002). Inconsistencies and discrepancies were found to be among the major limitations in studies carried out on disabilities in Saudi Arabia (Abouammoh, Al-Zahrani, Al-Twajiri, Tamim & Al-Twajiri, 2007). Secondly, there is a reluctance within the Saudi population to participate in research on disability due to cultural misconceptions and negative experiences. It is not unusual for families to feel ashamed about having a child with a disability and as a result they avoid contributing to such research (Al-Gain & Al-Abdulwahab, 2002). Previous experiences and a fear of helplessness, continued dependence, being housebound, having a low quality of life and a lack of productivity have been reported as reasons explaining why families can be reluctant to participate (Al-Gain & Al-Abdulwahab, 2002). A very recent article in Alwatan newspaper by Alshehi (2017), a Saudi journalist who writes about different social injustices, wrote that while the Kingdom has celebrated the World Day of Disabled Persons on December 3rd, we rarely see them in our streets or in public places. He said "*Where are the disabled whom the government fund and aid? No one knows. How do they live their lives? How do they spend their time? We still don't know. Why don't we see them in our community? I don't know? Neither do we see them at our*

social events, parties or festivals. Last year I saw them in a special event made for them in a shopping mall, a short one though, however real life isn't a shopping mall?"

Unfortunately, it is the harsh reality about disabilities in Saudi despite all the media coverage, social change rhetoric, and all the claimed funds allocated by the government for the past 30 years. Thirdly, all the research and surveys that have already been conducted in Saudi Arabia have been typically on a generic disability without direct focus on ASD (Al-Gain & Al-Abdulwahab, 2002).

It is noteworthy that all of the studies discussed in the first section "The Social Context of ASD" have been conducted and carried out in the US and Europe. Likewise, all of the resulting interventions, programmes and training have so far been designed to meet the expectations and needs of Western cultures and environments. Non-Western countries can benefit and learn from these studies and programmes as they give us a rich insight on ASD and its related ongoing issues, but ideally, they should investigate the nature of their own requirements, based upon the distinct cultural needs and challenges of that country. There is a developing evidence base that geographical and cultural differences play major roles in determining family reactions to, and coping with, having a child with disabilities (Krulik, Turner-Henson, Kanematsu, Al-Ma'aitah, Swan & Holaday 1999; Duvdevany & Abboud, 2003; Shu & Lung, 2005). It is therefore crucial to study specific cultures and societies in order to determine the nature of local services that will be effective in meeting the needs of these families in each specific culture.

A number of informal sources suggest that there is government interest in finding out more about ASD; namely, a personal meeting [May 2007] with a neurologist who works with children with autism in King Faisal Specialized Hospital and Research

Centre (KFSH&RC); a phone call [February 2012] with the Deputy Executive Director for Research in Prince Salman Centre for Disability Research (PSCDR) in Saudi Arabia (Riyadh); and an article in Alriyadh newspaper [2007] all confirmed that the Saudi government is investing in long-term financial, material, and human resources in order to improve epidemiological knowledge of ASD disability.

More recently, tremendous efforts to advance ASD in KSA such as collaborating with prestigious universities' research centres and service providers (Center for Autism Research, 2014), offering scholarships to graduate and medical students along with postdoctoral fellows interested in basic and clinical research (Ministry of Education, 2015), and approval to cover the cost of private schools for children with ASD (King Salman Center for Disability Research, 2014). However, current ASD services are still limited with little information available about them (Alnema et al., 2016). Besides, both services provided by governmental and private autism centers are insufficient with some important and essential services recommended for children with autism which are simply not available (Babatin, Alzahrani, Jan, Alkarimi, Jan, 2016).

Despite the fact that autism is on the rise, in the Middle East and specially the Gulf Cooperation Council (GCC) there is still a general scarcity in the literature examining autism in the region (Kelly, Alireza, Busch, Northrop, Al-Attrash, Ainsleigh & Bhuptani, 2016). A study by AL-Salehi, AL-Hifthy, & Ghaziuddin (2009) supports the fact that few reports have been published about the prevalence of autism in developing countries especially in Asia and Africa. Studies from the Middle East on this topic have been particularly rare (Afifi, 2005), and specifically in the Gulf Cooperation Council (GCC) (Kelly et al., 2016). Therefore, any recent studies and papers which have been

published in SA are still dependent on two old studies dating back to 2005 and 2009 (e.g., Al-Jarallah, Al-Waznah, Al-Nasari, Al-Hazmi, 2005; Al-Salehi, Al-Hifthy, Ghaziuddin, 2009).

Although accurate statistics of autism in Saudi Arabia are not available, informal and anecdotal records suggest a regional increase in ASD prevalence (Al-Zahrani, 2013; Zeina et al., 2014). A study by AL-Salehi, AL-Hifthy, & Ghaziuddin (2009) reported that there were 42,500 confirmed cases of autism in 2002 in Saudi Arabia, but many more remain undiagnosed. A more recent report on autism prevalence in Saudi Arabia was discussed by its publisher Dr. Al-Wazna, in a daily 60-minute television talk show called “8 O’clock with Dawood”, (show No. 234 on 17th April 2013). This TV program is Saudi Arabia’s first talk show addressing every day political, social and economic topics. During the program, it was stated that this report was supported by King Abdulaziz City for Science and Technology (KACST) and King Saud University (KSU). This was the only official national report to reveal that the government is planning and supporting research, including employing qualified professionals and establishing centres for autism in Saudi Arabia (Aawsat newspaper No. 11893, 2011; 8 O’clock with Dawood, show No. 234 on 17th April 2013). According to this national report dated 2008, the estimated number of autistic individuals in Saudi Arabia is 120,000. This translates to about 8:1000 live births. I contacted the program presenter and KACST to obtain a copy of the report that provides further information and details regarding the study, but did not get any reply from either. In addition, I reached out to some contacts asking their help in getting a copy of the report, but no one managed to find it. During my field work in Riyadh (2014 to 2015), I tried again to find a copy of the

national study by contacting KACST and KSU, again to no avail. It is the only cited study everyone talked about in Riyadh yet no one had managed to get a copy of it. Everyone I ask about the study replay "*I heard about it never have seen it*".

Recently, I came across a published PhD conducted by Alhudaithi (2015) in the UK, about Saudi Arabian female teachers' attitudes towards the inclusion of children with autism into mainstream, where that national study had been acknowledged. When I checked the publication part I found the same referencing I already had, again I emailed KACST and KSU asking them for a copy of the report and their reply was the same "*that such a study does not exist in their data*". Quoting the data of the national report published in the PhD, Al-Wazna (2008), reported that there are more than 100,000 autistic children who are at school age in KSA and the ratio is 6:1000. Interestingly, that is slightly less than what the same physician who was in charge of the national report claimed himself live on the TV program.

Another study cited in the same PhD by Halwani (2008), reported that autism has been estimated to occur in as many as 6 to 32 in 1,000 Saudi individuals". Also, he identified that autism has no racial or social associations and said psychological and social specialists help families create a plan for care, with heavy emphasis on diet and nutrition (Alhudaithi, 2015). The referenced link for this study in the PhD thesis could not be retrieved and all attempts to find the study were not successful. Additionally, in the Saudi Ministry of Health website (2017), autism ratio is reported to be 1 in 100 without citing any references to that study or how the data was obtained. Overall, estimates of ASD prevalence in the kingdom still vary between sources with no data about the confirmed cases of ASD in KSA are available.

There is an even greater paucity of resources for managing ASD in the country. What ASD services there are limited to only a few major cities in KSA and families from outside of these cities need to travel to those cities and/or outside the KSA to receive ASD services. This contemporary movement provides an interesting backdrop for researching ASD in Saudi Arabia. On the one hand, there is an absence of documented data on the prevalence and incidence of ASD in Saudi Arabia, a lack of a clear system for research into autism and its impacts on parents (mothers in particular). There is also an absence of any official agency responsible for compiling such information. On the other hand, some provision of services for children with autism exist through the work of specialist centres. Thus, ASD in Saudi Arabia faces a situation in which services for ASD are being implemented and provided before reliable research has been conducted to identify the services needed. Although a large-scale epidemiological study would be a good starting point for mapping the situation of ASD in Saudi Arabia, undertaking such a task is difficult to achieve single-handedly within a PhD research project. However, an ethnographic study that investigates family experiences and the cultural context of coping and managing circumstances such as living with children of ASD in Saudi appears feasible and a significant step toward shedding more light on the overall issue, in which most of the basic information is still unavailable or inaccessible.

In conclusion, all the above circumstances in Saudi Arabia add to the already existing pressures and documented difficulties faced by parents with autistic individuals. Further research that looks closely at the ways Saudi families cope when raising and caring for children with autism is required and reported to be absent in Arab Gulf

countries (Salhia, Al-Nasser, Taher, Al-Khathaami & El-Metwally, 2014). In the talk show mentioned above, two mothers of autistic children were explaining their difficulties, their anger, and continuous disappointments from the minimum services provided to autistic individuals in Saudi regardless of the generous budget allocated by the government. One of the two fathers had echoed the same concerns of the two mothers but added a very important dimension to the subject by saying “*my wife is so tired and mentally unwell. She is going crazy due to her endless responsibilities toward our five autistic children with no available resources or services. She herself needs rehabilitation, our house has become a prison*”. Unfortunately, little attention has been paid to this important statement because the main focus has been directed to the reasons hindering the progress of the country’s national plan for autistic individuals which was introduced in Saudi about a decade ago. It was obvious to the viewers that the four parents were angry, frustrated, depressed, and disappointed by the general situation. Nevertheless, this scene has not changed much for these parents and their children.

Autism Centres/Schools in KSA

Generally, the government of the KSA supports the inclusion of children with Special Education Needs (SEN) into regular schools as well as existing state-run SEN institutions and centers. In KSA, the terms “Centres” and “Schools” for autism are used interchangeably and most of them are privately owned with only limited governmental funded ones. Most of these centers/schools are private (commercial) and segregated from mainstream schools. Additionally, these few centers are full of students and with

waiting lists stretching between 2 to 3 years. While the KSA government subsidizes each institute, they charge and collect a large amount of money per student (Alhudaithi, 2015). According to Alhudaithi (2015), these special education centers and institutes have been viewed as a “*lucrative commercial opportunity*” for their private owners.

The majority of children with autism in the kingdom who have access to services, usually receive it in private schools and usually the family pays the cost for these services (Al-Zahrani, 2013). Furthermore, Alnema et al., (2016) reported that some families travel to neighboring countries (e.g. Jordan, Egypt, Kuwait, Bahrain, Qatar, and United Arab Emirates) and/or overseas (e.g. United Kingdom and United states of America) seeking services for their children with autism, but no information is available about such choice and service. While some families self-fund their travel expenses, others may receive governmental funding. Despite the growing facilities and services available for those with disabilities, Saudi society’s views of such people tends to be still based rather on the traditional concepts of disability, assuming helplessness, continued dependence, being homebound, a low quality of life, and a lack of productivity. It has been widely acknowledged that in the KSA, ASD services in public sectors are significantly insufficient with limited access for referrals. Rather the majority of children receive their services in private centers or schools and their families pay for those services (Ministry of Education, 2012; Al-Zahrani, 2013; Alnema et al., 2016; Babatin, et al., 2016). However, both public and private special education services in the Kingdom are reported to still be difficult to access by the families (Almasoud, 2010; Alquraini, 2011). Furthermore, the few private centers/schools are mistrusted by

parents of children with autism, lacking in most services needed for these children, and with the waiting list up to 2 years (Alhudaithi, 2015; Alnemary et al., 2016).

What programmes there are, primarily serve children with mild disabilities (Almasoud, 2013; Alquraini, 2013), and are primarily located in urban areas which makes access for people in rural areas, where the majority of individuals with disabilities reside, difficult (Hussein & Taha, 2013). Funding available for families of children with severe disabilities is far below the cost charged by the existing private organization (Almasoud, 2013).

In this chapter, factors that could influence families' parenting and caring style, their perspective of disability in general and autism in particular and parents' involvement in their children's care have been discussed. These factors included the geopolitical setting, social, cultural and gender context in SA and how it may affect both the parents of children with autism and the researches in the country. The socio-cultural context of disabilities, autism and mental health in the region have been discussed to shed light on the general perspective of Arab people on disability. In addition, the chapter provided an over view of the current situation and the current services available for families and their children with autism. In the next chapter, I describe my methodological approach to exploring these issues further.

Chapter 3: At Home in the Field: Reflections from the perspective of a Saudi woman researcher

In this chapter, I will focus on the specific issues I encountered while conducting my fieldwork among members of my own society in Riyadh, Saudi Arabia. I will also discuss my own prior experiences and how they shaped my desire to conduct this research from its inception.

Accessing the field

Even with the immediate advantages of speaking the same language with intimate knowledge of the vernacular and my familiarity with the people and the environment of Riyadh, a number of problems were still confronted and dealt with during the process of setting up and conducting this study. These included the necessity of abiding by the norms and roles expected of me as a native Saudi woman as I endeavoured to overcome the reluctance of the Saudi informants to share with me their experiences and views of raising a child with autism. It was necessary to understand how religion and culture helped them to contextualize autism, to understand intra-family conflicts and to decide upon which family matters could be shared with me, the researcher, and to what extent.

This is a hugely sensitive issue to all Saudis regardless of who is involved in that process or their educational backgrounds. It is not unusual in Saudi for parents to refuse to participate in research on the grounds of feeling discomfort in discussing their children's problem with a researcher (Alqahtani, 2012). Even Saudi professionals in the

mental health sector in one study refused to be interviewed by a researcher, and opted instead to complete the interview questions in writing because the questions required a level of self-exposure that in turn made them uncomfortable in participating in person (Al-Solaim, 2009).

Having been separated for a number of years from my own culture due to residence and education abroad I needed to resocialize myself with Saudi culture and traditions. Having said that, I had been visiting Riyadh occasionally to see my family, and while residing in London for my academic studies I was still in constant contact with a number of colleagues, departments, charities for autism and mothers of autistic individuals. This enabled me to stay close to the topic of autism in Saudi and facilitated my immersion in the fieldwork.

I was already aware that conducting any research in Saudi culture would bring many challenges, let alone conducting ethnographic fieldwork and qualitative interviews with Saudi individuals about deeply personal and private matters. Interviewing people in Saudi and asking them to talk at length about very private family matters is not something that Saudis would be expected to take lightly as they are unaccustomed to such a research process.

This can be understood in the light of Saudi cultural norms. Firstly, the family in Saudi society offers its members a sense of security and warmth, where families prioritise time for one another and share material goods together. However, family domination over its members, such as the sacrifice of the individual for the general good, the "*stifling of intuitive*" (Pharaon, 2004. p. 358), and its oppression of female

members and its youth within the family, comes also at great expense (Pharaon, 2004). Within the Saudi family system, the father has the final say in most matters, placing the ultimate power in his hands. However, maintaining the family unit and traditions is considered the mother's key role. The mother's role is not only to reproduce successful generations, ensuring family continuity, size, and power, but her fundamental role is also to transmit the cultural and religious traditions which reinforce solidarity and loyalty to the family (Pharaon, 2004). These conventions shape everything in Saudi family life. Therefore, whether to share concerns about their child's health, how much to reveal about it and with whom, is very important within Saudi culture, which would usually require a family decision, even if for the purposes of research. The family is the core of Saudi society and all its members are collectively obliged to abide by its code of conduct. Therefore, if there is any dissent or reluctance to take part in research, particularly from male members of the family, then no-one in the family would be allowed to contribute.

Secondly, most research conducted in Saudi to date is usually quantitative in nature and takes place in hospitals, different governmental or private centres or in official charitable societies and organizations. Saudi is a survey research (usually quantitative) dominated context (Honan, Hamid, Alhamdan, Phommalangsy & Lingard, 2012). The most popular research method in Saudi is sending out questionnaires to be completed and returned back. Nowadays, sending questionnaires via emails or via phone applications (e.g. WhatsApp), is a very popular (Kadi, 2018). One very attention-grabbing comment from a very experienced worker in a non-profitable organization dealing with parents of autistic individuals said to me "*Even if people agree to welcome*

you in their own home, would you go to someone's house that you do not know at all?. Also, don't forget that it will require you to have a driver to go around to these houses spending lots of time to get the answers. You will change your mind soon, and I will remind you of this conversation, believe me, it has been years since I joined this line of work and I know that the fastest and useful way to get mothers to answer questions is to send out the questionnaires to be completed, we have been helping lots of researchers in this effective way and we get the forms back in a couple of weeks or three months maximum. Why do you choose this way which will complicate your research and life? I cannot understand you".

I recall hearing this last comment and writing it down in my field diary. It made me think about my whole research method and try to see it in the light of Saudi culture, which caused me great anxiety. It was a stark reminder that qualitative research is rare in the Middle East and by no means a familiar tool (Al-Makhamreh & Lewando-Hundt, 2008; Le Renard, 2014). Le Renard (2014), said that is rare for researchers in the social sciences to be able to conduct fieldwork on a "city of closed space". She also stated that the few Saudi academics she met were surprised that she was able to conduct any ethnographic research in Riyadh. She also states how the scarcity of this type of research methodology in the area has led to a very limited understanding and awareness of many social behaviours and attitudes in our own culture.

Conducting ethnography in Saudi is imperative if we really aim to deeply understand our very own Saudi culture in the light of its own characteristics and distinctions, which have always been described as kind and warm, yet very conservative and private.

Going into the Field

My decision to conduct my field research in Riyadh, my own home town, was motivated by both academic and personal reasons. All my studies until graduating from King Saud University (KSU) and my work experience with special needs children, was in Riyadh, the capital of Saudi Arabia, where my family also reside. Therefore, my cultural identity and my prior academic background and interests had obviously affected my choice.

Growing up in Saudi, and more importantly working in such a profession with Saudi families, had immensely informed my deep obliviousness to the fact that having a child with special needs is indeed a humiliation and a stigma in Saudi culture. In 1994 I graduated from KSU with a bachelor's degree in special education with just twelve other graduates from this department. Only four of them went on to work in female special schools for the deaf and blind, and the rest worked in mainstream schools citing that "*It is very hard psychologically to work with disabled individuals*" or "*my heart cannot bear seeing them*". I went on to work in a government residential centre for intellectually and physically disabled children and female adults. I was the head teacher for four classrooms with three teachers' assistants. There were seven children in each classroom. They were also residents in the centre in another section called 'the children apartments'. When they had finished their academic and therapeutic sessions they would go to their residential apartments which were located within the centre. In the apartments, usually staff from outside of Saudi (e.g., from the Philippines or India) looked after the children as most of them stayed without their parents due to the parents

other family responsibilities. In addition, most of the families came from outside of the city, and it was costly for them to come on daily or even weekly basis to visit their children. Our work was to prepare an individual educational plan for each child, centred around his/her abilities and disabilities, and evaluate it every month. Also, my work involved coordinating with the child's mother to come and stay as a resident with the child to learn from other team members (e.g., occupational therapists, speech therapists, motor therapists) about how to continue working with the child at home when their treatment period finished or they moved to another facility.

Through working for years in different care centres for disabled children and adults, I came to form relationships with their families, or mostly, with their mothers. Mothers are the main carers for their family members in Saudi, so working together with them was paramount to my work with their child or family member. This way of building bridges with Saudi mothers of children and adults with special needs, back in the 90s, has informed much of my understanding of disability in Saudi culture, where such a subject is rarely discussed publically. I had no recollection of studying anything about cultural or religious belief, or the influence of parental backgrounds on such vital matters during my four years of study in KSU and was struck by this stark neglect of family and cultural context.

During my work, contact with fathers was limited to only emergencies and when the mother was not available for contact. Saudi culture is well-known for its religious and conservative nature, gender segregation, and commonly practised patriarchy. Mothers or a female relative were our usual contacts and still commonly are. That said, I remember during those years too, that many mothers were not open to nor welcomed

those one-to-one interactions. They usually preferred to receive letters or phone calls as a means of communication, and when we talked on the phone they kept their conversations to a minimum. Also, they rarely attended any events in the schools or centres. At the very beginning of my working career, I did not understand why these mothers did not want to get involved and failed to understand the unspoken subtext. When mothers did not respond to our attempts to contact them or include them in their children's care, myself and my colleagues had three stock answers ready: "they are very busy with other family commitments", "they do not care" or "they are ashamed of their child's disability". When the last response was selected to describe a mother's disengagement, it was always voiced in a hushed-up manner by all of us and rarely did any of us openly discuss anything about this, or even try to find possible solutions.

During my work in the residential unit in Riyadh, I noticed that few of the children with disabilities would ever leave to visit their families at the weekend. In fact, many never went on any visits nor had ever been visited by their family. Only after working for a couple of months, did I start to feel that these children had been neglected and abandoned by the family. The reasons cited by families varied (e.g., the child is hard to deal with, financial burden, or the house facilities do not support a wheelchair). I was told by the social worker at the unit that many families in fact are ashamed of their disabled children and did not want other families and friends to know about their existence. Some of them went as far as to move house or changed their landline phone number, so it would be impossible for them to be contacted or found by the center.

It was very intense personal experience to witness this and work with limited knowledge on the matter, simultaneously with a community who knew very little, if

anything, about what was really going behind these doors, including my own family. I still vividly remember their answers when I told them that many children and adults in these centres are abandoned and neglected by their family. They would reply *“No way, no Saudi family would do this, we are a Muslim nation and Muslims won’t treat children like this”* or *“Are you sure they are Saudi children and their families are pure Saudi?”*.

A couple of years later, in a step to expand my knowledge and improve my working skills, I decided to join a new mainstream kindergarten which was one of the few and first kindergarten in Saudi to embrace the idea of including and integrating children with disabilities alongside other able-bodied children. In Saudi this is called *“Damjj”*. However, at that time the Saudi perspective and understanding of integration meant that the students with special needs attended separate (and segregated) classes within a regular school building but did not attend any of the same classes and rarely came into contact with the other able-bodied children. It is almost quite the same system still nowadays (Alhudaithi, 2015). Nevertheless, this was an exceptional move and a great step forward for children with special needs in Saudi, to be included, seen, recognized, and be part of our culture, albeit not fully integrated or included.

What I was not prepared for was the harsh response from many highly educated mothers of the able-bodied children, many of whom had not long returned from years living in the US or the UK to complete their own education. We were expecting that these Saudi mothers would be supportive and encouraging of these changes. However, what we found was that they were upset and against the idea of integration, believing that their children were going to learn “bad behavior” and become themselves like the disabled children, which would ruin their education and progress completely. We

provided these mothers with academic articles from the US and the UK, which rejected such an argument by providing academic evidence of great benefit and progress to both groups from integration, but to no avail. In fact, some mothers actually withdrew their children from the school. The sadness on the face of the mothers of children with special needs was unforgettable to me as it was mixed with shame and pain.

This event was another learning point in my career, which made me aware of how complicated and rejected such children are in Saudi. Also, it informed me of another fact, that we culturally inherit many ideas with no critical thinking or research on the issue and its meaning to our culture. Since this was a private school with annual fees for its services, with wealthy middle and upper class parents who themselves had good educational backgrounds, I had assumed that they would support the idea of integration and be accepting of such children, or at least that they would not strongly reject it. Unfortunately, this was wrong. More importantly, my other assumption was that mothers from a wealthy and educated background would not be ashamed of a disabled child and would welcome their inclusion in their own child's education and progress, which was also incorrect.

The idea that was accepted amongst most Saudi people at that time, for example if they watched a foreign program about disability, was that Saudi mothers were in a much better place because "They have the family support unlike the West" and "Muslim people treat children with disability better". Unfortunately, that was not the case.

During this time, I was also struck by the isolation and apparent sadness of the mothers of the children with disabilities. I noticed that they stay apart and were also not

included by other mothers in school events, even though their children did not attend these events. I remember many remarks I heard from these mothers when they came to me for a meeting to discuss their children's plans and progress. Soon I learnt that one purpose for them in attending such meetings was for them to express their frustrations and hopelessness, and this has stayed with me all my life up until this moment. A couple of sentences will always remain alive with me such as; *"Do you think my family understands what I am going through? Of course, they help me but at the end they are not living with me"*, *"People stare at my son in the supermarket it is embarrassing, so I decided with his father that we would not take him out to protect him from this"*, *"We are alone in this as no one understands or really helps"*. I learnt the sad truth that many parents actually left their disabled child behind with the maid alone, when they travelled abroad, to avoid the embarrassment of being seen with a disabled child in public. This fact was hard for me to understand. These meetings were always emotionally charged and some of the mothers used to contact me at home on a daily basis for help. It was really hard to discover that lots of things we culturally supported and purported to believe in, were far from the truth. More importantly, this façade did not help the reality of these mothers who lived in silence and tried to show a different face in public.

At that time, people with disabilities did not exist in public places at all. Nowadays, views on disabilities have come a long way, but it is still a censored topic within Saudi society and even within families. In current Saudi culture, you would usually only see disabled people in public if there was a special event for them (as

these types of events have become more frequent in Saudi) but the reality is still that they are rarely seen publically accompanying their family in normal daily life activities.

In Saudi between 1990-1998, public awareness about disabilities was scant and its platforms were limited to a few newspaper articles, a few interpreted programs on the local TV channel, and limited academic theses. In most cases, individuals with disabilities would be kept away, out of sight, even from other members of the same extended family. This is despite of our deep religious beliefs which colour all aspects of our lives and would have it that such individuals should be cherished and looked after as they are the source of our blessings (*barakah*).

Getting around in the field

I was born and brought up in Riyadh, the capital city of Saudi Arabia and graduated from KSU with a bachelor's degree in special education. I had been brought up in a Saudi family dedicated deeply to the country's cultural heritage and the observance of its cultural mores, even while sometimes selectively practising and exercising a little independently from the cultural norms that would always stay within the family. This is a way of living most Saudi individuals are aware of, and rarely speak or discuss openly, except to someone who shares the same level of openness or is very trusted in the safe keeping of such a disclosure. Thus, most Saudis collectively follow the cultural standards expected from them publicly, and demonstrate outwardly what is culturally expected.

Altorki (1988) is a Saudi anthropologist who grew up, studied, and lived most of her life in Egypt, a country she also considered home. She also spent several years in

the US and explained that she was always reminded by her family that she could not follow certain practices and values performed by her Egyptian college girl-friends simply because they did not fit with Saudi's traditions and expectations, and as such, such conduct would not be acceptable in Saudi.

Publicly, every Saudi individual is expected to abide by common cultural norms even if they feel indifferent or not concerned about them. You will always be voluntarily reminded by your family, relatives, or friends about these traditions and their values, even if accidentally overlooked. Consequently, this way of living will affect how Saudi people publically engage with each other and what family information will be exchanged between them as well as with strangers, regardless of their status. This is a way of living that I myself experienced all my life growing up in Riyadh. Traditions in Saudi are always represented through vivid images usually drawn from parents' and grandparents' way of life. The traditional institution of the family also entails compliance with family and religion. In turn this is linked to the continuity of the past through following family traditions and has provided young Saudi people with a sense of security and identity at times of serious changes in their lives (Yamani, 2000). Tradition, even within the new Saudi generation, is filtered by religion and culture (Yamani, 2000).

Despite my familiarity with Riyadh as my native city and my deep understanding of Saudi culture, I was still subject to all these same social expectations and constraints throughout my fieldwork. Being a Saudi woman, I knew that I could neither travel alone in the country nor live alone by myself. All Saudi women live with their families until they get married then they move out to their husband's house, so living by myself during my time in the field in Saudi was out of the question. This role extends to Saudi men

too but with far less restrictions on them, by virtue of being males. Most Saudi males live in their family house until they get married and move out, though some of them chose to stay with their family even after marriage. Therefore, being a Saudi woman in my own country, even as a researcher, meant that I must assume the many roles and positions attributed to me, such as being the daughter of a good family who also conforms to the Saudi code of conduct. Thus, conducting my field work in Riyadh city where my family resides seemed most appropriate and most convenient for these reasons.

Whilst travelling between Saudis' cities is not a problem as most of these cities have airports with many flights scheduled daily from the capital Riyadh and vice versa, the real problem was that I would have needed a male member of my family as my guardian (*mahram*) with me at all times. This was simply because I could not drive by myself to get around or rent a place to live by myself, as women are not allowed to rent a place without a male guardian signature on the contract, as well as being present throughout the whole process. Hiring a local taxi by myself would also not be a welcome idea either to my family or Saudi people in general. Taxis (a "limousine" in Saudi dialect) is more popular in Riyadh than in some other big cities where they are considered dangerous and Saudi people use them very rarely, and only in very dire situations when no other means of transport is available. Some Saudi families would go as far as to make it clear to all their family members that taking a taxi is never allowed. Le Renard (2014), explained that Saudi women considered taking taxis in Riyadh to be "Too dangerous" and "lacking prestige". She described how using a taxi to get around in Riyadh for her own research was her only option for transportation as women in

Saudi cannot drive and the city lacks a public transportation system. Yet many Saudi women warned her from taking these taxis alone, telling her that the city is an unsafe place where many crimes, rapes, and kidnapping occurred.

The lives of many Saudi females have been literally halted because their male guardians did not permit the use of taxis nor provide them with a licensed family driver, as the latter is becoming a very costly option to provide. Due to such reliance on male relatives, women are being confined to the home and cannot commit to personal activities which require any form of travel (e.g. finish their studies, work, or go out socially). In some households, women are not even allowed to use this only accessible means of transport even to go to a hospital appointment. Instead they must always rely on a father, a brother, or a husband to take them anywhere.

When Uber launched its service in Riyadh in early 2014, Saudi tradition shifted very slightly for having such a service. Although many Saudi families had been accustomed to using Uber abroad and trusted the service and allowed their daughters, wives, sisters to use it, still many of them were opposed to its use when they are back in Riyadh.

Some of my close relatives and good friends are not allowed to use Uber when they go back home to Riyadh, despite doing so when abroad. Some of them are really upset and disappointed by their family's position, while others accept such arrangements. I asked them what kind of answers or justifications they would get from their guardians (e.g., father, brother, husband or son) when questioned about their position of refusing. One said "*My husband told me that I'm not allowed to use Uber in*

Saudi no matter what and he doesn't want any questions". Another said "My father told me our daughters don't ride in Uber, if he can't take me to where I want to go and my brother can't, then I should stay home" and they "the men of the family" will take me out another day". One friend said "Both my father and husband said to me Saudi is different, the community is different here than outside of the country as both of them don't allow us to use it in Riyadh". One brother told his sister "I don't want you to use it in Saudi because I don't trust Uber's Saudi drivers". An old and respected educated woman told me that all the males in her family, who are also highly educated, agreed that the reason that they are against using Uber in Saudi is that "Most Saudi families are not used to that, they are not ready yet and they don't want to be singled out for using it but will when everybody does". This example shows how many cultural and social mores are embedded in the mind of Saudi individuals, regardless of their educational achievements or wider international experiences, and passed on through generations. As a result, everyone continues to follow them even if the traditions have no grounds or simply are regarded indifferently.

For the purposes of my research, I used and relied on my own family's drivers to get around to conduct my field work. I was fortunate that my family had the means to afford a private driver and also to be afforded the right to use this by my family. Relying on my own family's licensed professional drivers meant that I could move around freely and safely to conduct my field work and to meet and interview my informants at their own convenient time, knowing that a car would always be available for my work needs.

From the perspective of the insider/outsider researcher, being at home in Riyadh, I was spared having to worry about the issue of adjusting to the society, a benefit

enjoyed by others who have worked within their own society (Altorki & El-Solh, 1988). Neither did I need a visa or to find a place to rent and live in. I went directly to my family house and settled down immediately, whereas Le Renard (2014) was faced with practical difficulties with regards to being a foreign Western researcher conducting her ethnographic research in Riyadh. She explained that to obtain her visa as a Western woman she had to be sponsored by a Saudi official body (King Faysal Centre-in her case), and through them she was invited as a researcher to Riyadh city and guaranteed a visa. Even for research matters a local sponsoring body is needed to obtain a visa to Saudi which is usually a very complicated process for Western researchers. Furthermore, accommodation was a big issue for her, due to a limited budget and her requirement for a short-term rent, as such a service was not available in Riyadh and if it was, it would be will above her research budget. She was not successful in renting a room within a Saudi family house which might be a cheaper option. Personally, I am not surprised by that due to my deep awareness of Saudi cultural particularities. She could not find nor could convince anyone to agree with this arrangement simply because they feared hosting a Western person in their house (Le Renard, 2014). In addition, the traditional gender segregation in Saudi culture would not make such an option feasible either to a foreigner or to a local person.

Gender segregation in Saudi extends to almost every aspect of life and takes different shapes in everyone's daily life such as: educational places, employment, banks, and even shopping malls where some dedicated special sections/floors are only for women, allocated to them on certain days. Gender segregation is dutifully adhered to in most Saudi family households, where even males and females from the same

family are separated during weekly family gatherings such as over lunch/dinner (in that I mean the males/females cousins/relatives do not mix and each group sits and eats separately in different rooms in the house). In Saudi life, most social events and activities which involve both genders are in reality done with meticulous gender-based segregation. Indeed, gender segregation is considered a unique element of the Saudi identity as well as the Saudi nationality.

Le Renard's attempts to integrate herself, a western female, into Saudi culture, whilst admirable, would prove almost impossible. Accommodating a complete stranger, specifically a Westerner and a female, into a Saudi household would simply not be culturally acceptable. Furthermore, within Saudi culture the presence of Western individuals, let alone a female researcher, would usually trigger discomfort and wryness between Saudi people. Saudi after all is not an open country for foreigners, except for working purposes. Even when working visas are offered to foreigners, they would usually only be offered to males and their presence in the country will be under very restricted rules. Westerns working in Saudi will usually live in a protected compound, where Saudis are not allowed in without permission. While Westerners can be seen in Saudi shopping malls, restaurants, supermarkets etc, they typically interact only with other foreigners, and rarely with Saudis. Indeed, even non-Saudi Muslims would need to obtain a visa before being allowed to perform any religious commitment in Mecca or Medina (holiest sites in Islam) and would not be permitted to move freely between other Saudi cities.

Identifying with the field

I was fortunate as a native Saudi woman that I did not have to overcome these same barriers and restrictions, to conduct research in my native home town of Riyadh. The people I studied saw me as one of them. They saw me as a Saudi woman, belonging to a Saudi family, and as such I was recognized and known by some of them. Others directly knew members of my family. As such, I was known to some as the daughter of or a cousin of or a sister of a friend, while to others as a member of a lineage they knew from other mutual friends, which is how Saudi people recognize and identify each other (Altorki, 1988).

This provided me with advantages, like other researchers conducting research on their own society. Stephenson and Greer, (1981) argue that knowing one's culture enables the researcher to select the research agenda based on what is the most expedited way to achieve the task and mostly achievable within the limits of what will be allowed by the subjects under investigation.

This cultural and familial familiarity helped to open many doors to me for conducting research within Saudi culture. However, this did not come without limitations and complications. I found that being closely known to someone, through a friend or family member could also work as a barrier in certain areas and block that door completely. While Altorki (1988), gained access from being well known to her informants because of the kinship ties and the friendship between the families she knew, it did close many doors to her. Altorki wanted to study the social life of the elite, their family organization, rituals, and customs and to document how these have

changed for the younger people in the study. There was no 'shame' attached to such a topic of research for Altorki, as opposed to the embarrassment and shame attached to the subject of having an autistic child within the family. That said, Altorki (1988), admitted that certain information would be withheld even from her if it was likely to reveal anything that the family did not wish to expose publicly. Thus a degree of formality was always maintained with her, regardless of the trust she gained through kinship ties with these families.

In Saudi culture, our family name is a form of "ID" to other people in Saudi and when we talk with someone we do not know, the first thing we usually do is to introduce ourselves with our first name followed by our last names. It is a clear indicator of the family we come from and their roots, and from which one can know a lot about the other person.

All the participants in my interviews were not previously known to me. However, my family name was identified by them, it was passed on by mutual contacts and was also printed on the study information sheet. This enabled potential participants to know something about me, who I am and the family I come from. However, almost none of mothers who participated in the interviews revealed their family name (last name) to me. This was a surprise given our code of social conduct. I failed to notice the reason for this at the beginning and out of Saudi courtesy I politely asked them who I was talking to. Most of the answers, were '*umm flan*', which means mother of either her daughter's or son's name (sobriquet *umm flan*). They did not disclose their family name to me because they wanted to protect and safeguard their identities and personal information from the public, even with a researcher who was Saudi herself. I initially conceived of

this as a disadvantage, until I realized how to turn it to the research's advantage. From that point onwards, I started all my other telephone conversations with any new potential participant by emphasizing that her family name was not a concern and I did not need it for my study. On the other hand, my family name was always a topic of conversation for all participants. This point of unreciprocated self-disclosure proved important for establishing safety and confidentiality with my research participants.

Final Reflections on the field

Reflecting on the journey I have been on, from first working with children with disabilities and their families as a teacher in Saudi, and more latterly as a researcher, there are common threads about wanting to better understand the experiences of these families and raise awareness of their difficulties. In conducting this research, I have, however, had to be careful not to just see what I set out to see.

It has been imperative to include many validity checks throughout the research process, from designing the interview schedule, through conducting the participant observation and interviews to analysing my field notes and interview transcripts. These are discussed more in the Methods chapter, but include consultations with other clinicians and academics (both Western and Arabic), as well as my supervisory team and academic peers. I have sought to be as transparent as I can in my interpretation of my findings and enabled the Saudi mothers' voices to speak for themselves as much as possible. Nevertheless, the reader should be aware of my prior experiences and motivations for exploring this topic further.

Being a Saudi woman conducting qualitative and ethnographic research in Saudi has been an almost unprecedented and certainly challenging endeavour. My status as a Saudi woman from a family in Riyadh, has, however, also made doing this research possible. My family name and position helped to open doors and infer trust (although not without exceptions) in most cases. It also meant that (with persistence) I was allowed to volunteer in and observe at different centres for autism. I had access to my family's driver which meant the practicalities of travelling around Riyadh and meeting participants in the confidentiality of their own homes was possible. I also had the support of the female and male members of my family, without which none of this would have been possible.

This has given me a 'home advantage' over other researchers from Western cultures who might be interested in exploring this topic in Saudi. However, it may also have conferred certain 'blind spots'; things I was not aware of because I am also invariably a product of the same culture as my research participants. Working with non-Saudi colleagues, I have encouraged curiosity and challenge, to enable me to question and evidence my interpretations. I similarly encourage the reader to explore and question the lens through which I have conducted this study.

Chapter 4: Methodology

This ethnographic study explored how Saudi mothers caring for a child with autism recognised and understood autism, their cultural beliefs and understanding of autism, and how they adapted and coped with their concerns, worries and needs regarding their children.

The selection and use of an appropriate and applicable research methodology play a significant role in managing the research process; in determining how data will be collected and in ensuring that data will address the identified aims of the research (Salehi & Golafshani, 2010). Therefore, this chapter provides an overview of the methodological approach used, the rationale for its selection and reflections on the methodological issues which arose.

An ethics application for data collection was submitted on the 4th of February 2014 and was approved by UCL Research Ethics Committee on the 28th of April 2014 with the ID number 4986/001 (see Appendix 1).

Methodological Approach

I used two ethnographic methods: participant observation and qualitative interviews. Qualitative research can provide a rich foundation for new ways of defining questions and carrying out research (Fetterman, 2010). Its methods are useful when working in previously unexplored territory where theories have not yet been developed or tested.

Ethnography

Ethnography is one of the common approaches to collecting and analysing qualitative data. It is the study of social interactions, behaviour, and perceptions that occur within groups, teams, organisations, and communities. In essence, an ethnographic approach is oriented toward studying and understanding shared meanings and practices in a specific culture, with an emphasis on understanding the insider/local perspective (Guest, Namey & Mitchell, 2013).

The central aim of ethnography is to provide a holistic insight into people's (taken for granted) actions, grounded in the nature of the location in which the interaction takes place. This is achieved through the collection of detailed observations and interviews (Hammersley, 1995). Relatedly, "*ethnography is about telling a credible, rigorous, and authentic story*" (Fetterman, 2010, p.1). Desmond (2014) stated that "*direct contact is essential to understanding the meanings people make in their worlds and the actions, beliefs, and ideational, social and environmental structures that shape those worlds*" (p. 32). Hence having "*direct contact*" with research participants is key to the ethnographic approach. As direct contact entails going into the field, Gupta & Ferguson (1997) put it this way, "*Fieldwork's stress on taken-for-granted social routines, informal knowledge, and embodied practices can yield understanding that cannot be obtained either through standardized social science research methods (e.g., surveys) or through decontextualized readings of cultural products (e.g., text-based criticism)*" (p.36).

Monaghan & Just (2000), summed up the simple idea of ethnography, which is in order to understand what people are up to, it is best to observe them by interacting with

them thoroughly, deeply, and over an extended period of time. Being there, available to observe, available to follow up, available to take advantages of the chance event, are all key to ethnographic success. Thus, *“It is this openness to the serendipitous discovery”* (Monaghan & Just, 2000, p. 19) that imbues ethnographic method with its inductiveness and flexibility.

An interpretive paradigm

This study was situated in the interpretive paradigm. According to interpretivists, *“interpretive methods of research start from the position that our knowledge of reality, including the domain of human action, is a social construction by human actors and that this applies equally to researchers”* (Walsham, 1993, p. 5). Knowledge, in interpretive perspectives, is constructed by individuals based on their interaction with, and of, the world around them. As summarised by Geertz (1973) *“what we call our data are really our own constructions of other people’s constructions of what they and their compatriots are up to”*. Meaning exists in complex cultural, social, and institutional milieus of individual experience (Crotty, 2003). Interpretive researchers attempt to understand phenomena from meanings assigned to it by participants.

An interpretive perspective seeks to reveal multiple realities as opposed to searching for one *objective* reality. It searches for deeper meaning in personal narratives, observed behaviours, and activities (Geertz, 1973). Denzin commented *“objective reality will never be captured. In depth understanding, the use of multiple validities, not a single validity, a commitment to dialogue is sought in any interpretive study”* (Denzin, 2010, p. 271).

Ethnographic research, conducted within an interpretive paradigm, thus involves interpreting both the experiences of the participants and the lens through which the researcher is filtering their analysis. I adopted an interpretative approach in this study.

Sampling and Recruitment

Sampling method

Qualitative research sampling aims to select participants whose responses and answers enable the researcher to gain a deeper understanding of the phenomena being studied (Creswell, 2013). I used purposive sampling as described by Guest, Namey & Mitchell (2013) to select participants who would offer and provide rich and informative accounts with regard to my research interest. In Bernard's words, "*you decide the purpose you want your informants (or communities) to serve, and you go out and find them*" (Bernard, 2000, p. 176). The power and logic of such sampling lies within "*selecting information-rich cases for study in depth...those [cases] from which one can learn a great deal about issues of central importance to the purpose of the inquiry*" (Patton, 2002, p. 230).

Patton (2002) outlines sixteen purposive sampling approaches and the different purposes they serve. I used the snowball/chain referral sampling approach. This is a reputable method for identifying and accessing hidden and hard-to-reach populations (Atkinson & Flint, 2001). I chose this approach because I was reliant upon social contacts, interviewees, professional colleagues, and professional networks in SA to contact resource centres and potential informants. Via these initial contacts, I then

endeavored to recruit participants who were diverse in their knowledge, education and views on the subject.

Sample Size

The sample size in qualitative research is usually small (Gall, Gall & Borg, 2007). That said, Kvale (1996), advised researchers to “*interview as many subjects as necessary to find out what you need to know*” (p. 101). He explained that the number of participants can be small or large depending on the research subject and the point at which further interviews will not offer any additional information. The signal to the end of data collection task is deemed “*when you begin hearing (and believing) the same answers over and over again*” (Barrett and Cason, 1997, p. 106). This point at which data does not add any further depth to the topic is known as “*saturation*” (Strauss & Cobrin, 1998). In other words, the researcher must continue to include participants until no new themes emerge or *data saturation* has been attained. Qualitative researchers study fewer participants compared to quantitative studies, as their emphasis is placed upon gaining a subjective and in depth understanding of the participant’s lived experience, as opposed to a broad and generalisable perspective (Creswell & Plano-Clark, 2011).

Inclusion criteria

Since the inclusion criteria for this study was to select participants who would provide rich information with respect to the purpose of the study, the inclusion criteria for selecting the mothers were that all mothers should be Saudi and have a child who had

been diagnosed with autism. The age of the child was not specified as the study was concerned with the mothers' experiences of having a child with autism. The study did not include mothers from different Muslim neighboring counties who resided in Riyadh.

Field Sites

The different sites I contacted and visited for accessing participants were:

- A governmental hospital and research centre with a centre for autism research located in the centre of the city centre. It is considered one of the first hospitals for diagnosing autism in Saudi and still very popular due to its autism centre.
- A governmental hospital and medical city located in the east of the city. It was the second hospital to be involved in diagnosing autism.
- Another governmental hospital located in the heart of the city.
- A private centre (school) for autism (male/female centre) located in the north of the city. It is a specialised centre/school for children with autism only. The children attend in the morning and finish by the end of the day then return to the family home.
- A charitable organisation for individuals with autism in the family. They register the families of autistic individuals in their system and offer support and knowledge on governmental funds and help for their children.
- A governmental day care centre for autism located in the west of the city, where children with autism are taught and trained.

- A private School for children with autism located in the north of the city. Another school for teaching and training children with autism.

I carried out observations at two sites. These were a charitable organisation for families of autistic individuals and the other one is a governmental centre for autistic children. The other sites were contacted, visited and provided with all the required letters and information, however they declined to take part in this study.

These two sites had different roles in regards to autism. One registers the families of children with autism in their system in order to help direct them to the right process. Those families usually come from all parts of the Kingdom looking for ways to seek help and advice for their children, due to their lack of knowledge about autism and how to deal with it. Most of these families are unaware of the governmental available support for autism. They really need one-to-one guidance in all the steps, from how to register their children in the system up to obtaining these subsidies. Additionally, they required hands on support to achieve the above. As discussed earlier, due to the lack of a central statutory body for autism in SA, these families lack the information, support, and guidance to attain the help required for their children and the support they need themselves. This organisation (The Families of the Autism Society) is the only charitable organisation providing this service in the kingdom. In addition, this service is collecting demographic data for these families as the official prevalence of autism in SA is still unavailable. The other site is a governmental day care centre for autism, which is included in an inclusive rehabilitation centre for individuals with intellectual disabilities and with mobility impairments. The children come in the morning and leave by noon.

Recruitment of field sites

I used my existing personal and professional connections to contact sites prior to my arrival to SA. In Saudi culture, personal connections and family name play an important role in opening closed doors, easing discomfort, and enabling trust towards the researcher and the topic of the research.

Once in Riyadh I met with the service directors, to explain what kind of help I would need from them and to answer their questions. I visited sites several times to explain the nature of my research. I gave a commitment to help and support them and offered to attend the centres on a daily basis if they required it. I felt initially they were sceptical about my offer. One site director asked me to come for four days a week to help the teachers with their daily tasks of training the children with autism. Another director said *“would it be ok to come three days a week to arrange the files of the new joining families of autistic individuals and help the staff?”* I replied *“yes I am happy to help with that”*. She continued *“I don’t understand why do you complicate your study, when we can take your questionnaire and send it to many mothers to fill and bring back?”*. I answered *“I am grateful for your concern towards my research and its speed, and reassure you that I will seek your advice and help if required”*.

I assumed different positions in these services, from going into the classroom to assist the teachers to sitting with the director discussing some of their issues and concerns and trying to find ways to address them.

Recruitment of participants

One month after commencing observations at the field sites, I discussed with the director different ways of approaching mothers to invite them to participate in the qualitative interviews. While being in both sites, I had the opportunity to be introduced officially by the director or an assigned teacher to many mothers from different backgrounds. Also, it helped me to gain access to speak independently with different mothers about my research and provide them with contact information in case they wished to participate.

In addition to the above, mothers of children with autism were recruited through colleagues, friends, and family members. Personal connections and social networking are extremely important tools to use for recruiting participants in Saudi culture as trust tends to follow from these connections and networking. Colleagues, friends, and families' members put me in contact with potential participants.

Recruitment procedures

Any mother who expressed interest was provided with brief information about the research and the different ways to contact the researcher (i.e., my mobile number and email) if they were interested in participating or discussing the study further. I invited potential participants who contacted me to decide whether they would prefer to meet at a school/center or organisation which provided me with a base or for me to come to their home. Each time I met or called a potential participant mother I give a brief explanation about my study, the topic of interest, the way they would be interviewed and

the time scale involved, so that they could make an informed decision as to whether to participate. I also elaborated on my possible attendance for any events related to the child with autism which the mothers might attend, and if they would agree to my observing them. In addition, I kept a copy of the topic guide questions handy to show whenever any of the mothers about the type of questions I would ask them (see Appendix 2 for a copy of the topic guide in English). As for the consent form for the teachers and staff, I provided both sites with evidence of the ethical approval, the participant information sheet and the consent form which was given to the directors (see Appendix 3 and 4 for a copy of both the information sheet and consent form in English). In both cases, the directors took this information and said they would explain themselves to the teachers/staff the reason of my attendance and presence which should be adequate as per their instructions. I also carried out a couple of meetings in both sites with the teachers and staff to tell them about my reasons behind observing them and the importance of this in my research.

To respect the participants' rights to confidentiality and to protect their privacy; I have used pseudonyms throughout to replace all actual names of the participants and their children.

Characteristics of the sample

I recruited 23 Saudi mothers of children with Autistic Spectrum Disorder. Brief demographic details of the participants are shown below in Table 1. More detailed information about each participant is presented subsequently.

Table 1: Demographic Information of mothers

	Mother's Name*	Mother's Age (Years)	Education Level	Father's Age (Years)	Education Level	No. of Children	No. of Children with Autism	Child's with autism's Order Among Siblings	Child's Age at time of interview (Years. Months)	Age when problem was noticed (Months)	Age when diagnosis was made (Months)
	Umm Hamad	36	Undergraduate academic degree	37	Doctor	2	1	2 nd	7	28	48
	Umm Saleh	37	Undergraduate academic degree	46	Undergraduate academic degree	2	1	1 st	4	18	30
	Umm Adel	40	Undergraduate academic degree	43	Undergraduate academic degree	4	1	4 th	6	18	26
	Umm Johara	33	Undergraduate academic degree	35	High School	4	1 (twin)	2 nd	5	14	24
	Umm Hamid	29	High School	34	High School	1	1	1 st	5.2	9	31
	Umm Madawi	38	Undergraduate academic degree	38	Undergraduate academic degree	2	1	1 st	10	24	48

	Mother's Name*	Mother's Age (Years)	Education Level	Father's Age (Years)	Education Level	No. of Children	No. of Children with Autism	Child's with autism's Order Among Siblings	Child's Age at time of interview (Years. Months)	Age when problem was noticed (Months)	Age when diagnosis was made (Months)
	Umm Khalid	48	High School	50	High School	5	1	4 th	19	24	60
	Umm Sami	56	Undergraduate academic degree	64	Undergraduate academic degree	5	1	2 nd	31	24	24
	Umm Zayed	44	Undergraduate academic degree	50	Undergraduate academic degree	6	1	1 st	19	24	30
0	Umm Rakan	49	Undergraduate academic degree	50	Undergraduate academic degree	5	2	4 th , 5 th	13, 10	3weeks, 42	42, 72
1	Umm Malik	44	Undergraduate academic degree	50	Diploma	2	1	2 nd	7	24	42
2	Umm Ahmad	26	High School	34	High School	2	1	2 nd	5	18	36
3	Umm Faisal	52	High School	65	Undergraduate academic degree	6	1	4 th	23	36	84

	Mother's Name*	Mother's Age (Years)	Education Level	Father's Age (Years)	Education Level	No. of Children	No. of Children with Autism	Child's with autism's Order Among Siblings	Child's Age at time of interview (Years. Months)	Age when problem was noticed (Months)	Age when diagnosis was made (Months)
4	Umm Sultan	45	Undergraduate academic degree	57	Undergraduate academic degree	2	1	2 nd	9	12	48
5	Umm Saad	34	Diploma	44	Diploma	3	1	2 nd	10	14	48
6	Umm Mohammad	36	Undergraduate academic degree	43	Doctor	4	1	3 rd	7	18	60
7	Umm Judi	30	Undergraduate academic degree	48	Diploma	4	1	3 rd	4.8	36	39
8	Umm Moudi	38	High School	43	Diploma	4	1	2 nd	15.4	18	84
9	Umm Tareq	36	Undergraduate academic degree	44	Undergraduate academic degree	3	1	3 rd	8	24	32
0	Umm Ali	30	Primary School	37	Primary School	4	1	4 th	3.8	6	24
1	Umm Sarah	39	Postgraduate	42	Undergraduate	4	1	3 rd	7	2	60

	Mother's Name*	Mother's Age (Years)	Education Level	Father's Age (Years)	Education Level	No. of Children	No. of Children with Autism	Child's with autism's Order Among Siblings	Child's Age at time of interview (Years. Months)	Age when problem was noticed (Months)	Age when diagnosis was made (Months)
					academic degree						
2	Umm Nawaf	39	Undergraduate academic degree	48	Undergraduate academic degree	5	1	3 rd	10	24	48
3	Umm Turkey	50	Undergraduate academic degree	60	Undergraduate academic degree	3	2	2 nd , 3 rd	20, 18	24, 24	48, 48

*Please note that pseudonyms have been used to protect the participant's anonymity

Participants

In the Saudi culture it is common practice to refer to parents by the name of their first-born child (e.g. Umm Malik, Abu Zayn) which literally means mother of Malik and father of Zayn. This convention is known as a *Kunya* in Arabic. In the Saudi culture the *Kunya* go always by the name of the oldest son even if there is an older daughter. The mothers in this study chose to identify themselves as Umm (name of child with autism) so this is the practice has been reflected here. However, the names of the children have been changed to protect the anonymity.

Umm Hamad is a 36-year-old housewife with an undergraduate academic degree. Her husband is a consultant. They have two children who are both male. The second child is a 7-year-old who has been diagnosed with autism on numerous occasions. The last diagnosis he received was at aged four. They live in an upper middle-class area as a nuclear family with one maid. She invited me to her house for the interview.

Umm Saleh is a 37-year-old with an undergraduate academic degree. She is a working mother with two children. She is divorced from her husband due to the continuous disagreement about the best way to deal with her autistic child's medical issues besides autism. The father's refusal to believe that his son was autistic, even after two were diagnoses made in different hospitals, made life unbearable between them. Since the divorce, she lives with her children in her parents' house. Her daughter is a 3-year-old while her son is a 4-year-old who was first diagnosed with autism at the

age of two and a half years old. She does not have a maid, but her parents have one. I met with her at her sister's house for the interview. Her sister stayed with us for the first ten minutes then she left us in the guest room to carry out the interview.

Umm Adel is a 40-year-old housewife with an undergraduate academic degree. She has four children. Two of them are adults at university, the third is a teenager and the youngest is a six-year-old boy who was diagnosed with autism at the age of two and a half years old. They live in an affluent area as a nuclear family with two maids, where one in particular was brought in to look after Adel and tend to his needs. She invited me to her house for the interview. Her child with autism came to the guest room, but the maid escorted him out immediately.

Umm Johara is a 33-year-old working mother with an undergraduate academic degree. She has four children. The eldest is a six-year-old girl and the second are 5-year-old twin girls, in which one of them was diagnosed with autism at the age of one. The last child is a two-year-old boy. They live in an apartment in a newly developed area on the outskirts of Riyadh city without a maid. She and her husband moved to Riyadh for the sake of their autistic daughter where most of the services and diagnosis for autism are available. They used to live in a small town with very limited medical services. She invited me to her house for the interview. Her daughter with autism and her twin came and sat with us for a few seconds then they left the room at the request of their mother.

Umm Hamid is a 29-year-old divorced mother with a high school certificate but no job. She has a five-year-old son who was diagnosed with autism at around three years old. She and her son live with her mother in a very small one bedroom apartment. The apartment is located next to her married elder brother who pays the rent and looks after his mother's expenses. They live in an old and poor neighbourhood in Riyadh, also popular for immigrant workers and foreign labour with cheap and affordable rent. Her former husband does not provide for their son for any of his needs and does not visit or ask about him. Her brothers however do help to pay for her son's medical and educational needs. In addition to this, Umm Hamid is also receiving support from friends who are aware of her circumstances and are supporting to pay for her son's annual tuition fees and are trying to find her job opportunities. She invited me to their apartment for the interview. When we finished our interview she called her mother and introduced us.

Umm Madawi is a 38-year-old working mother with an undergraduate academic degree. She has two daughters. The first daughter is a 10-year-old who was diagnosed with autism at the age of four. The second is an 8-year-old. She lives with her husband and children in an affluent neighbourhood with one maid in the house. She invited me to her house for the interview. Her daughter freely came and went throughout the interview with no restriction from her mother.

Umm Khalid is a 48-year-old housewife with a high school certificate. She and her husband have five children. Her fourth child is a 19-year-old who was diagnosed with autism at five years old. They live in a

government compound in Riyadh next to his father's work. It is a middle-class family with a maid in the house. She invited me to her house for the interview and when I arrived, she told me that she wanted to conduct the interview at her neighbour's house next door. We went together to the neighbour house and she introduced me to her. Her neighbour stayed with us for the first 20 minutes of the interview then left us and came later to join after we finished our interview.

Umm Sami is a 56-year-old with an undergraduate academic degree who just recently retired. She lives in a very big house in an affluent area with her husband and their five adult children. Her son with autism is the second born and he is a 31-year-old who was diagnosed with autism at the age of two by a visiting foreign doctor for Dhahran, Saudi Arabia. This is a city located in the Eastern province of the Kingdom and it is a major administrative centre for the Saudi oil industry where the family used to live at that time. Due to limited facilities for treating autism in this region, Sami was sent to a special school in Jordan where he resided from the age of 12 to 19, visiting his family only in the holidays. The family subsequently travelled to America to a centre for Autism to seek guidance on how to manage Sami's behaviour. It was noted that the main issue was Sami's uncontrollable anger as he became an adult. He once pushed his 65 year-old father which resulted in his father having a broken shoulder. At the age of 31 and with no available services in Saudi, Sami was sent to Dubai to a residential facility, where he now lives with several visits made by his mother throughout the year. I was invited to interview her at her house.

Umm Zayed is a 44-year-old working mother with an undergraduate academic degree who is involved in various charitable activities relating to families with autistic children. Her autistic son is their first child and he is a 19-year-old who was diagnosed with autism at the age of two and a half years. He has five other siblings. After his initial diagnosis in Riyadh, they decided to take him to the US to be diagnosed again by experienced professionals in the field of autism as the diagnosis process they had in Riyadh was not convincing or professional enough. They also spent time in a training centre in the US to learn how to deal with his situation. This family do have a higher income in comparison to some of the other families that were interviewed, which allows them to have a lot of resources such as a number of maids in their house. They hire a private male teacher who comes every day in the afternoon to teach their son and take him out in the car, as there are no services or facilities in SA for individuals with autism at his age. She invited me to her house for the interview.

Umm Rakan is a 49-year-old working mother with an undergraduate academic degree. She has five children. Three of them are adults who are studying at university. The last two of her children were both diagnosed with autism. The first is a 13-year-old who was diagnosed with autism at the age of four, while her youngest is a 10-year-old who was diagnosed with autism at the age of six. She lives with her husband in a middle-class area and they do not have a maid. She invited me to her house for the interview, but then decided to rearrange for it to take place at an autism centre.

Umm Malik is a 44-year-old housewife with an undergraduate academic degree who is looking for a job. They have two children and both are boys. Her second child is a 7-year-old who was diagnosed with autism at the age of three and a half years. They are a middle-class family and live in a medium house with no maid. She decided to meet in a quiet café for the interview. She did not bring her sons, but showed me lots of pictures and videos of her autistic child. She remained veiled throughout the interview with her *niqab* where it leaves only the eyes uncovered.

Umm Ahmad is a 26-year-old housewife with a high school certificate. She has two children, both boys. The second is a 5-year-old who was diagnosed with autism at the age of three years. She lives with her husband and the children at his family house as an extended family. They live in a modest residential area. She invited me to interview her at their family house. Her mother-in-law was with us in the room throughout the whole interview.

Umm Faisal is a 52-year-old mother with a high school certificate. She has her own business. She has six adult children. The first three are adults who finished their university degrees and married. Her fourth child is her 23-year-old son who was diagnosed with autism at the age of 7 years in the US. The other two are in their teenage years. They are a wealthy family and live in an affluent area well known for its grandiose houses. Her son with autism lives abroad in Kuwait in a residential facility for autistic individuals, as no such facility is available in Saudi. She received me at her private working office in a very secluded area of her grandiose house.

Umm Sultan is a 45-year-old working mother with an undergraduate academic degree. She has two sons. The second one is a 9-year-old who was diagnosed with autism at the age of four years. I met with her at her parents' house. It was a very big house in an affluent neighbourhood. She has a 22-year-old nephew who was also diagnosed with autism, but leads a successful life in a US university. Her family history includes high incidences of autism after being genetically screened. She decided to put her son in a boarding centre for autism in Jordan after taking him to different autism centres in Riyadh and not liking the service provided. She goes and visits him a number of times throughout the year, but his father had never accompanied her to visit his son. She invited me to her parents' house for the interview.

Umm Saad is a 34-year-old mother with a diploma degree. She has three sons. Her second is a 10-year-old who was diagnosed with autism at the age of four. They live in a house next to their family members and relatives. She has a maid. She is the manager and advocate of the “hero Saad” with another active mother which is a “WhatsApp based group” for different mothers with autistic children. They advocate for mothers with any issues related to autism and offer to help them with how to deal with them. They provide one to one advice, offer videos or put them in contact with experts to help them to understand how to manage their children's situation. They provide all the services for free as *sadaqah lillah* (charity for the sake of Allah-God) with the *niyyah* (intention) that it is an ongoing charity, the reward of which will by Allah's leave, reach their autistic children and alleviate their difficulties. She spoke on Saudi TV about autism and the dire

need for services. She publicly spoke of her own depression and the isolated life she was in, which was due to her first realization of having a child with autism, before discovering that taking antidepressant medication under the care of a psychiatrist could be helpful. I interviewed her at her house. Her son came and joined us for a couple of minutes then left the room.

Umm Mohammad is a 36-year-old housewife with an undergraduate academic degree. She has four children. Her third son is a seven-year-old who was diagnosed with autism at the age of five years. She lives with her husband and children in small house in a newly developed area on the outskirts of Riyadh city. She was initially unsure if she would like to participate in this research but wanted to see for herself what it is all about. She subsequently agreed and gave verbal consent to being interviewed.

Umm Judi is a 30-year-old housewife with a college diploma. She has four children. Her third daughter is almost five years old and diagnosed with autism at the age of three years. She lives in an apartment with her husband and children with no maid. She invited me to her place for the interview. The interview took place in the family living room with three of her children around us. Her husband had to leave their apartment until we finished to give us the space and time for the interview. Her 12-year-old son stayed in the guest room next to us due to my presence, which he? considered as a strange woman in their apartment.

Umm Moudi is a 38-year-old housewife with a high school certificate. She has four adult children. Her second child is a fifteen-year-old teenage girl who was diagnosed with autism at the age of seven years. They live in a house in a middle-class area with a maid. She invited me to her house for the interview. When we finished our interview she called her daughter to the room to introduce her then she asked her to leave after a few minutes.

Umm Tareq is a 36-year-old housewife with an undergraduate academic degree. She has three sons. The third son is an eight-year-old who was diagnosed with autism at the age of two years and eight months. They live in a house with a maid. I met with her for the interview in their house. Her child with autism came to join, but his mother asked him to leave us after a few minutes.

Umm Ali is a 30-year-old housewife with primary education. She has four children. Her last child is a four-year-old boy who was diagnosed with autism at the age of two years. They live in a small apartment in a humble neighbourhood that is known as a community neighbourhood for people with limited income. Her husband left their place during the time of the interview. At the beginning, she introduced all of her children and they stayed with us during our coffee time. She then asked them to leave so we can start our interview, but left her autistic child to come and go freely all the time of the interview.

Umm Sarah is a 39-year-old working mother with a PhD degree. She has four children. The third child is a seven-year-old who was diagnosed

with autism at the age of five. They are upper middle-class family with one maid, who moved to Riyadh city to access services for autism. She invited me to her house for the interview. When I reached to the house, she welcomed me at the outside door and suggested to have a walk together in the little park across from her house. During our walk and talk about general topics, she decided to rearrange for another day to meet again. We finally met in a hotel lobby for the interview and she remained veiled throughout the interview with her *niqab* where it leaves only the eyes uncovered.

Umm Nawaf is a 39-year-old housewife with an undergraduate academic degree. She is involved in various charitable work relating to families with autistic children. She has five teenage children. Her third son is a ten-year-old who was diagnosed with autism at the age of four. I met with her at her parents' house. It was a very big house in an affluent neighbourhood. She had decided to prepare a will with a lawyer solely for her autistic child. Such an act is not usually practised in Saudi culture where details of the Islamic inheritance are already prescribed in the Quran and meticulously followed by all Saudi people. She wanted to protect him from being placed in a residential facility after the parents passed away and assigned two guardians for the task who are her brother and her uncle. She invited me to her parents' house for the interview. Her sister-in-law was present at the beginning of the interview, but then she left us and came back at a different time.

Data Collection

Participant Observation

I carried out observations at site 1 for four days a week from 7:30 in the morning until 1 or 2 o'clock. This took place from April 2014 until the end of December 2014. At site 2, I observed for three days a week from 4 in the afternoon until 7 or 8 in the evening. This took place from March 2014 until December 2014.

Participant observation is known to be both the most natural and yet the most challenging method of collecting qualitative data. The method helps the researcher to be connected to the most basic human experiences which takes place at a particular context by full immersion and participation from the researcher in that context. Only then would the researcher be able to discover and understand the how and why behind human behaviours taking place in such context (Guest et al., 2013). Therefore, it is not enough to be in that particular social milieu Guest et al., (2013) explained. In participant observation, the researcher takes notes and asks questions with the intention of uncovering the many meanings behind various behaviours. The researcher hopes to discover, understand and analyse aspects of different social scenes which might use rules and norms expressed or practised tacitly by the participants and operated on automatic or subconscious levels. Or such conventions may even officially be off limits for discussion or taboo. In so doing, the researcher in participant observation is trying to generate meaningful data which can add to and deepen our

collective understanding of human experience (Guest et al., 2013; Spradley, 1979). Spradley (1979) explained that “*most cultural themes remain at the tacit level of knowledge*” (p.188) with a big part of any culture consisting of tacit knowledge. While people know and apply the cultural principle to organise their behaviour, and interpret and clarify experiences, they do not express them easily (Spradley, 1979). Therefore, Spradley (1979) explained that ethnographic analysis consisted of searching for the parts of a culture, the relationships among those parts and the relationship of the parts to the whole. Consequently, the ethnographer must then “*make inference about what people know by listening carefully to what they say, by observing their behaviour, and by studying artefacts and their use*” (Spradley, 1979.p. 9). He also emphasised the importance of making inferences which usually go even beyond cultural knowledge that is communicated directly by manner and language.

Going to two different sites for a number of months and talking with directors, staff, teachers and mothers of autistic children as well as attending different formal and informal meetings and events, provided me with an opportunity to understand the relationships and the dynamics between these places and the mothers of children with autism. The main objective of such a method in these different contexts was to understand the arrangements, activities, harmonies and tensions between different players (professional, nonprofessional, staff, and families of ASD). With time the informal conversations allowed me to uncover and understand the complexities and nuances in the relationships between teachers/staff and the mothers.

My position and presence in such sites helped me with not just writing down ethnographic notes from my direct observation, but in clarifying these notes throughout the days with the people (i.e., directors, teachers, and staff) I was working with. This allowed me to ask questions to uncover or explain the meaning behind the behaviour, actions or the decision making I observed in an event or incident. Guest et al., (2013) described participant observation as an interactive and relatively unstructured qualitative technique, which excels in capturing three elements:

- 1) Rules and norms that are taken for granted by experienced participants or cultural insiders.
- 2) Routine actions and social calculations that happen below the level of conscious thought.
- 3) Actions and thoughts that are not usually recognised as part of the “story”.

Researcher role

I took a participant stance and carried out any work, such as filing, or took the position, observing or working, that the director in each service asked me to take. One director said “*once you arrive in the morning come and see me, I will see what you can do*”. The other one said “*we have a lot of work with a shortage of volunteers at the moment, so each day comes with different tasks for you, are you ok with that?*” I replied “*I am ok with that*”.

The first two weeks I used to go directly to the directors' offices as I was led by the staff and spent most of my day with them. Both of the service directors would let me stay with them most of the day and asked me to join them through their rounds. While I walked with them, they introduced me to most of the teachers and the staff with a brief introduction about my attendance. After two weeks I carefully started to ask the director if I could help with anything as I was physically away from the teachers and the staff in the administration section. Also, I noticed whenever I approached anyone in the school they responded very formally and reservedly. I wanted to break the ice and to be able to blend and work with the teachers and the staff. I also wanted to observe how the day started and finished and to be part of that.

For a week the director let me help in arranging files with a staff member and prepare letters for the new students. While being with the staff filing I quickly started to gain access to the teachers and was able to watch the arrival of the children every morning. Both the staff and the teachers started to warm up a little but kept their distance from me. Into my second week of being with the staff, the director came and introduced me to them and gave me the opportunity to explain in more detail about my work and why I am helping and working with them. She also asked to meet with the teachers at the end of the day to introduce me to them as well. Only towards the end of the first month, was I able to start working directly with the teachers and allowed to join them in the classroom and go around the building with them. At this point, they started to ask me more questions

about my work, especially why I wanted to join them instead of just sending my interview questions to the mothers. Throughout many informal and formal conversations, I had the chance to answer their questions and ask them questions too. At the beginning of my second month the director told me that she herself will introduce me to the participants' mothers or appoint a teacher to do so if she is busy with another task.

Familiarisation period and note taking

Initially I did not write notes throughout the day, but once in the car at the end of my day I would write down key headings, to be elaborated upon once I was home. I chose not to write notes on site because I did not want the directors, teachers or the staff to feel uncomfortable or cause any mistrust or suspicion about the field notes I was taking. In both of the sites, I used to note headings and key words about the day as soon as I was in the car at the end of each day. Once I reached home I would immediately go into a private and quiet room and elaborate on the details of each point. After three weeks, as my role started to become more organised, my field notes started to take shape and have different headings such as; being with the directors, being with the teachers, being with the staff, formal meetings, informal meetings, training sessions for the teachers, training sessions for the mothers, different observations, and events for autism.

After a month I decided to approach the service directors and explain to them about the idea of me having a diary or note book to write down some of my field notes related to my work in situ and to seek approval for that. It

took a couple of explanations about the information and the purpose of the notes I was planning to collect, until they agreed. From there on, I used to write headings and words down at key points during the day, and later on in the evening fill them out and elaborate. It enabled me to quickly jot down words or notes about incidents where later on I could write down more of the details.

Once I started to bring my note book to both field sites, I made sure to write my notes between the breaks or when other teachers or staff were taking time to write and organise their work. Once a teacher said "*what are you writing about us?*". Another said "*you might go and report to the directors*". I offered for them to look at my notes. They actually did. One commented "*so you just write down the times and what are you doing and little descriptions of your role and what is happening?*" I replied "yes" then she said "*we shouldn't worry*" with a laugh I said "*of course*". Nevertheless, in order to protect confidential information, I made sure to keep my field notes book safely on my person or in my room, at all times. In addition, I did also use the voice recording function on my iPhone to verbally record some important events and their details if I knew I would not have time write notes on that matter until sometime later. These audio notes were then later that day transcribed, and then listened to again with the transcription of the recording in front of me. This was repeated several times to confirm the accuracy of it.

One-to-one in-depth Interviews

Selection of method

Gall et al., (2007) consider the collection of the data to be at the heart of a research project. In this study, interviews were the core source of my data. I used one-to-one and in-depth semi-structured interviews. Semi-structured interviews involve preparing a list of questions or topics to be covered, yet staying open to changing the words, forms and order of the questions based on the interviewees' answers (Rubin & Rubin, 2011; Brinkman and Kvale, 2015). Semi-structured interviews are designed to lead the conversation into the topic of interest and are deliberately openly structured to maximise the opportunity for discursive, detailed, and highly textured responses. Semi-structured interviews also allow for further inductive probing questions during the interview in which the interviewees are encouraged to share and elaborate on their understanding, beliefs, experiences and viewpoints (Guest et al., 2013).

Open-ended questions were employed to let participants take whatever direction they wanted, to use their own words to communicate their experiences, and suggest topics and concerns that were crucial to them (Rubin & Rubin, 2011; Patton, 2015). These questions allowed the mothers to express their beliefs and concerns deeply and unconditionally, and allowed the conversation to flow where it desired and needed to understand their experiences and meaning making around ASD.

Being attentive during the interviews helped to ensure that I conducted my interviews in a way that promoted the dignity of my participants. Honoring peoples' dignity involved the following; respectful and nonjudgmental listening, seeking understanding, and valuing the participants, experiences and stories (Hicks, 2011; Seidman, 2013). In summary, one-to-one in-depth qualitative interviews were chosen to gain as much information as possible, and to enable the research questions to be investigated in detail and depth and to better understand the real situation of these mothers.

Development of topic guide

In developing the topic guide, I first discussed potential questions and checked them with my supervisor. Then the evolving topic guide was sent to a consultant clinical psychologist who spoke English and Arabic fluently. This colleague was asked to look at the English questions with regard to cultural sensitivity and concern. Once she approved it, I asked her to translate the questions to Arabic. In addition, I sent the topic guide to a third bilingual colleague with qualitative expertise to check on the English questions and once approved, she was also asked to translate it in to Arabic. We compared all the three Arabic versions (my two colleagues and my own) and adjusted a couple of words to ensure that the questions were clear and in accordance with Saudi culture. Finally, the topic guide was tested to ensure its quality and clarity and discussed with three mothers of children with autism who provided feedback on the questions. Finally, the topic guide was piloted with two mothers of children with disabilities (not autism). The Arabic version of the topic guide is provided in Appendix 5.

Issues about mothers' recruitment through the sites

Going to these places and becoming part of them, I quickly learnt two facts. One is that the service directors and staff handpicked specific mothers for any research and blocked others from taking part saying “*These are good mothers, they do anything we ask them to do all the time and fill in questionnaires in no time and bring them back*”. The other fact was that by exerting their authority over mothers, these mothers felt obliged and pressurised to participate. This was something which I was certainly opposed to, but, unfortunately, was not given sufficient space to explain my views about.

To be practical and to respect their ways of dealing with things while at the same time not crossing the lines or interfering with their dynamics, I therefore followed their instructions to the letter. The typical way I was introduced to any mother by the director or the staff was “*This is doctor Taghrid, she is doing her research in London and has questions for you to answer, you are one of our cooperative mothers, so don't disappoint us, give her time and answer all her questions*”. They would usually then stay with me and the mother after introducing us, while I carried on explaining about the study.

I noticed that throughout the introduction and when we were accompanied by any staff members, mothers in general refrained from asking questions. Although their intentions for sure were to help me and the mothers, I wanted to take a different approach to such a delicate matter. I

wanted to make sure that the potential participants felt free to decline from participating without needing to provide reasons for that. Therefore, after six weeks of attending and working in these sites I felt I could talk to the directors and discuss different ways of approaching mothers. That is, after introducing me to the potential mother that they would preferably leave me with her to continue to introduce the study and to explain the way it would work. They did then agree to that. In that way, I made sure at least that any potential participants would feel free to ask questions and freely agree to participate or opt out from the study. I also gained enough time to elaborate about the interview and the importance of having enough time where we can talk and discuss things together. Besides, I explained to any mother I sat with that she is free to leave the study anytime without any explanation.

After meeting with around 7 mothers I learned that they actually would like to discuss the study further through the phone rather in the school/centre while the staff are around and asked me to provide them with a mobile number. Also, they asked me not to mention their preferred way of communication to anyone in the centre. Once they learned that I was fine with such arrangements, they usually cut our meeting short and told me "*I will contact you soon by phone where we can discuss things alone*" or "*It is much better to chat with you by the phone away from here, then I will let you know if I want to participate*". In addition, I was told by a mother that some other mothers told her that they refused to participate when the school staff asked them because they were concerned with the fact that I would share their answers with the school/centre. For these reasons, subsequent

recruitment was sought directly with the mothers, rather than through the directors or staff in the Autism services.

Interview procedures

The interview questions were prepared in two languages. English and Arabic, however all interviews were conducted in Arabic. Most participants were interviewed once and most of them took between five to seven hours. Just two participants were interviewed twice to continue as the interview was interrupted due to family issues and responsibilities.

All of the interviews in participant homes took place in the *majlis* (guest room), designed for guest and located in a quiet and isolated area from the house and usually away from the family living room. As Le Renard (2014) described it "*the receiving room (majlis), is destined for guests and the staging of the family in relation to the outside world*" (p.16).

At the beginning of each interview, I allocated around thirty minutes to get to know each other in person and engaged in open conversation while having the prepared Saudi coffee with dates/chocolate that is traditional and demonstrating my appreciation of the mother's hospitality. In doing so, I was trying to establish and gain rapport in addition to ensuring confidentiality and conveying empathy for a sensitive, emotional, and confidential subject that will be deeply discussed with the mother.

Establishing rapport between the interviewer and the interviewee enhances and improves the quality of the research, as described by Glesne (2011) "*people will talk more willingly about personal or sensitive issues once*

they know you" (p. 144). Furthermore, being sensitive to the cultural traditions and customs of Saudi mothers and waiting on their cues to start the official interview questions was vital in minimising misunderstandings and potential source of conflicts between us. Fielding (1994) believes that participants respond more favorably if they have things in common with the interviewer. Coming from the same community and sharing the same cultural background made it easier to pick up these unspoken rules and act accordingly. After that and before beginning the actual interview, I asked each mother in a conversational way the demographic questions, which served to gather background information about their family status, socioeconomic status and education level (see Appendix 2).

Usually once we finished drinking our Saudi coffee and before serving the tea, most of the mothers asked to start the interview's questions. I took the opportunity to ask them again and to check in person if they were still happy to consent to using the audio recorder to record our interview. All mothers allowed me to record the interview saying "*I trusted you enough to invite you to my house and share my family issues with you, so recording that would be safe forever*". Along the same lines, another mother said "*are you serious about asking me this question again? You would not be inside my house if I didn't trust you first*". So when I verbally confirmed with each mother that she was comfortable being recorded, I started the actual the interview.

I started with the questions included in the topic guide, yet stayed open to add or reorder them during the interview. Such an approach allowed

me to keep focused during the interview and ensure that all potentially relevant areas were covered, but also facilitated the flexibility to respond naturally to the discussion as it developed, incorporate new insights to the topic, respond to stories told by the mothers or answers their questions and perceive the dynamics of interview and build upon it instead of getting distracted by taking notes (Kvale, 1996; Brinkman and Kvale, 2015). In addition to its flexibility, this method responds to individual differences, and allowed me to create tailored questions which deepened our communication during the interviews (Patton, 2015). The use of a recording device for interviews was invaluable, as it offered me the chance to listen to the interviews several times, in order to transcribe the interviews and ensure that the comments of the mothers were properly reported.

In the interviews themselves, I addressed all mothers by the name they gave to themselves, and how they introduced themselves to me. In Saudi culture, mothers take the name of their first child, usually their first son and are hence called by *Umm* (mother of the name of her son). Calling a mother/participant by (i.e., Umm Hammad) shows respect and politeness and is considered more culturally appropriate than using her first name especially when two people barely know each other. I followed mothers' leads in such situations and called them by whatever they called themselves. All of the mothers I interviewed identified themselves to me by Umm then the name of her child with autism, even if it was not the eldest one. Just two mothers decided to share their first given names and their family's name.

Transcription

After completing each interview, I immediately transcribed it verbatim, and then listened again to the recording with the transcription in front of me. This was repeated several times to confirm the accuracy of it.

When the interviews were transcribed, all of the names were changed to pseudonyms to ensure that all mothers' identities and information were confidentially maintained in the transcribed interview.

Two professional transcribers and I separately listened to each recording with its transcription in front of us to confirm the accuracy of each transcription and discussed any differences with each other to clarify them. This first phase of data analysis, the transcription of the interviews from audio-recordings to written documents using 'Microsoft Word', was extremely time consuming, since I had more than 150 hours of recordings. However, it is important that the researcher prepares the transcripts with as much detail as possible in that it will help in allowing to gain a better grasp of the phenomena being studied.

I also used a diary journal to record after each interview my observations during the interview about the mother's body language and facial expressions.

Language and translation

This study was conducted in Saudi, where Arabic is the spoken language, however, the findings were to be presented in English as this is a

research project for a UK degree. Therefore, all interviews had to be translated from Arabic to English. Birbili (2000) reported that collecting data in one language and presenting the findings in another is becoming common among social research projects. Generally, two translation techniques are considered when translating participants' words. The first one is called the literal translation of the text, which means translating word by word. Whilst as Honig (1997) described it "this make one's readers understand the foreign mentality better. p.17", he also cautioned that such a technique could reduce the readability of the text. The second method, called the free translation, was described by Birbili (2000) as creating translations/quotations that read well. This means capturing the essence of the sentence, rather than literally translating it word by word. Such a practice has been criticised since the risk of misrepresenting the meaning of the conversational partner can occur in the process (Rubin & Rubin 2011).

For both of the above reasons, I decided to choose to translate the data using both techniques to preserve the meaning and readability of the text in the knowledge that I can return to the original text as often as possible until a level of satisfaction and clarity is reached. Furthermore, a certified translator, who has been involved in translating questionnaires, surveys, educational chapters, and novels from English to Arabic language, and vice versa, was involved in collaborating with this process.

Data Management of the Interviews and Participant Observation

As discussed above, organising the data was the first step in processing the qualitative data. It involved transcribing and translating the interview audio recordings and reviewing each interview carefully in order to begin to establish potential key themes and codes that were common amongst the participants (Creswell, 2013). I organised all the information gathered from both research methods and made it accessible by labeling audio-recorded files, interviews and participants observation transcription files accurately, keeping a duplicate copy of each file. I kept all files in a secure locked filing cabinet at all times when not in active use in my office which was accessible only to me. All electronic data (i.e., digital audio recordings and electronic copies of the interview and the participant observation notes in both language Arabic and English) were stored on my personal laptop, in password protected files with restricted access to me only.

Data Analysis

The data in this study was obtained using two specific ethnographic methods: participant observation and one-to-one in-depth qualitative interviews and both were analysed thematically. Thematic analysis is argued to offer three key components: accessibility, flexibility and usefulness as a research tool to analysing qualitative data (Braun and Clarke, 2006). It is an interpretive process involving total immersion by the researcher into the data

to identify patterns which provide an enlightening description of the phenomena (Smith and Firth, 2011). Thematic analysis is described as *“identifying and describing both implicit and explicit ideas within the data, that is, themes. Codes are then typically developed to present the identified themes and applied or linked to raw data”* (Guest, MacQueen, and Namey, 2012, p. 10).

Thematic analysis emphasises identifying common themes within the data. That is, themes which are important to the description of the investigated subject and are linked to the research questions. Braun and Clarke (2006), summarised the advantages of thematic analysis which include flexibility, it being a relatively easy and quick method to learn and do, generating unanticipated insights, usefulness in summarising key features of a large body of data, and offering a thick description of the data set. On the one hand, it can provide a wealthy, detailed, and sophisticated account of data. While on the other hand, it can be used within different theoretical frameworks, and not necessarily associated to any pre-existing one (Braun and Clarke, 2006).

Approaching the study from an interpretive viewpoint, I used an inductive or *“bottom up”* approach to analyse my data. Such an approach means to *“use detailed reading of raw data to derive concepts, themes, or a model through interpretations made from the raw data by the evaluator or researcher”* (Thomas, 2006, p. 238). An inductive approach means that the identified themes should be derived from and firmly linked to the data and not from any previously derived hypotheses (Patton, 2015). As such, inductive

analysis is a process of coding the data with no intention to fit them into a pre-existing theoretical framework, coding frame, or researcher's analytic preconceptions; rather the findings are directly developed from the analysis of the raw data (Braun and Clarke, 2006; Thomas, 2006).

For this study, I implemented the six suggested thematic analysis phases outlined by Braun and Clarke (2006). They are as followed:

Phase one: transcribing all the interviews and allowing me to start familiarising myself with the raw data (Riessman, 1993; Braun and Clarke, 2006). All of the interviews in this study were transcribed verbatim, which involved including full and accurate information without omitting any features of the participant's speech. According to Maxwell (1992), omitting such features of speech would threaten the validity of the research, which could be vital to the understanding of the interview. This stage included multiple readings and re-reading of the raw data and continued back and forth between the whole set of the data, during such a process I started to jot down ideas and potential codes.

Phase two: the analysis started when I initially generated a list of ideas about the data, then I started to identify initial codes. The coding process involved "*aggregation of the text or visual data into small categories of information, seeking evidence for the code from the data, and then tentatively labeling the code*" (Creswell, 2013, p. 184).

Phase three: started when I had all my data coded. This phase involved re-examining my analysis at a broader level, organising the initial

codes and the relevant coded data excerpts into potential themes. During this phase, it is suggested that the researcher can code individual excerpts of data into several different themes due to the fact that in this stage the researcher never knows what themes might be most interesting later (Braun and Clarke, 2006). Also, due to the flexibility of this approach, researchers can always establish themes in different ways, therefore researcher judgment is crucial to decide on potentially relevant themes. Ryan and Bernard (2003) suggested and listed several scrutiny and processing techniques for identifying themes. Repetition was one of them, which was utilised in this study to identify my themes. Repetition refers to ideas, concepts, or topics that occurred reputedly in the data. In other words, the more the same concept emerges in the data, the more likely it is a theme.

Phase four: This phase started when I had identified all my themes and involved reviewing and refining these themes by identifying their relevance to and providing an accurate representation of the data. This phase involved abandoning themes, creating new ones, breaking them down into separate themes and combining some into each other. This restructuring involved two levels:

Level one involved checking the themes in relation to the coded excerpts or quotes by reviewing all of the quotes for each theme and determining if it represent a constant pattern or not (Braun & Clarke, 2006).

Level two involved reviewing the themes in relation to the entire data set and establishing if they echoed "*the meanings evident in the data set as*

a *whole*" (Braun & Clarke, 2006, p.91). This phase ended when having a clear idea of what my themes were, how they worked together and what general story they indicated and suggested in accordance to the data.

Phase five: began when I established sufficient themes from my data. This stage involved clarifying and writing a detailed analysis of each theme. Also, trying to capture each story behind the theme and how each theme contributes to the overall story about the data. In addition, it is important to develop and name simple and clear headings to each theme which reflects the essence and the story behind it.

Phase six: was marked by writing up the final analysis and report. A detailed and balanced analysis was provided for every theme, supported by rich excerpts from the data to tell the reader a consistent and credible story about the data and contextualising it in relation to existing literature (Braun & Clarke, 2006).

Validity and Reliability

In qualitative research, a greater emphasis is placed upon the validation of the data analysis and the data interpretation rather than the study's reliability and generalisability (Creswell and Plano-Clark, 2011). Qualitative validation involves ensuring that the accounts from the researcher including all involved participants are accurate, credible and trustworthy (Creswell and Plano-Clark, 2011). From the above, it is vital to check the validity of the final list of the developed themes and the interpretation of the data. According to Ryan and Bernard (2003) some scholars consider

researcher judgments as one way to check theme validity where he/she makes the judgments clear and explicit, while other scholars recommend that the study participants review, comment, and confirm the accuracy of the themes/analysis (Patten, 2015). Others refer to the collective judgments of the scientific or research communities as a strategy to check the validity of the analysis (Bernard, 2011; Patton, 2015).

In this study, two validation strategies were attempted, member checking and peer debriefing. Unfortunately, member checking did not work in the cultural context of SA. I approached mothers and one said "*I am really busy and I can't go back and read 40 pages about our interview and I am not sure if I want to read what I discussed earlier*". Another mother was initially excited about such an idea, but then changed her mind saying "*I am too busy to look at it, I trust you with that*". The other strategy for validation used was peer debriefing, in which was subsequently employed twice, once at the beginning of finalising my themes and the other at the final steps of my final list of the developed themes. Detailed information on this technique will be discussed next.

Validity Criteria

All researchers seek to produce valid and reliable research findings and knowledge regardless of their research methods. Since qualitative research involves assumptions that support multiple realities and perspectives, the researcher's goal is to accurately represent those uncovered by the participants (Krefting, 1991). Therefore, in qualitative

research, a greater emphasis is placed upon validation of the data analysis and its interpretation rather than the study's reliability (Creswell and Plano-Clark, 2011). According to Merriam (1998) to ensure validity in qualitative research, the researcher should conduct the study in an ethical manner. Validity defined as "*the correctness or credibility of a description, conclusion, explanation, interpretation, or other sort of account*" (Maxwell, 2013, p. 122). In this study, credibility, transferability, and confirmability (Lincoln and Guba, 1985) were established as validity criteria to ensure the rigor and consistency of my research.

Credibility denotes the extent to which the findings of a study are believable and authoritative. It is outlined as "*accurately representing what the participants think, feel, and do and the processes that influence their thoughts, feelings, and actions*" (Lodico, Spaulding, and Voegtler, 2010, p. 169). Credibility in qualitative research can be established by using several methods such as; data triangulation, member checking and peer review (Creswell and Plano-Clark, 2011). In this study, credibility or validating the qualitative data was attempted by utilising the following methods:

- Member checks: which involves having the participants to review and confirm the accuracy of the interview transcriptions. Prior to the analysis and interpretations of the data, I called most of the mothers and asked each one if she can review and comment on the transcription, but all of them refused to be involved as discussed earlier. Instead, I attempted to increase the validity by listening to the audio recording as much as needed and comparing it to the

transcription in front of me to confirm the accuracy of it and clarify any ambiguity.

- Peer reviewing: which involves having colleagues, peers, professionals, or someone familiar with the phenomena being studied to review the research project, comment, and provide feedback. After finalising the coding process and identifying major themes, I engaged in peer debriefing with my supervisor, which include reviewing and evaluating the accuracy of the findings, the interpretations, and conclusions, and determined whether or not they were supported by the data. Also, an experienced researcher in qualitative studies and independent of the study was invited and asked whether the themes made sense and whether the interviews had any further themes by selecting randomly a number of interview transcriptions to check and review.
- Researcher's reflexivity: which includes researcher self-disclosing their biases, values, assumptions and theoretical orientations in which influenced the research process. I kept a research journal while conducting this study, where I noted and clarified how my expectations, experiences, and beliefs come into play in the research process.

Transferability is another commonly considered validity criteria in qualitative research (Lincoln and Guba, 1985). Transferability describes the concept of external validity, in which the findings of a study can be applied to other contexts or settings (ibid). In this study I provided thick, rich, and

detailed descriptions of the study to allow readers to understand, evaluate, and compare the phenomena in this study with those that they have explored in their research. In addition, Ponterotto & Grieger (2007) believe it is impossible to have 'thick interpretation' without 'thick description', as thick interpretation is required for the written report to possess credibility and resonance among the research society, the participants, and its readers.

Confirmability in qualitative paradigm is parallel to objectivity or neutrality in quantitative research, which could be established by developing an audit trail, a researcher reflective journal, a confirmability audit or external audit, and triangulation (Lincoln & Guba, 1985; Shenton, 2004; Creswell, 2013; Patton, 2015;). Since I approached this study from an interpretative viewpoint, I clarified my role within the construct of research knowledge to ensure confirmability. I tried to identify the views and perceptions that may influence my interpretations of the data, and acknowledged what has been highlighted, downplayed, and overlooked in the research. As Levy (2003) stated, "*this is not in order to suspend subjectivity, but to use the researcher's [my] personal interpretive framework consciously as the basis for developing new understandings*" (p. 94).

Ethical Issues

The reality of conducting research in SA raised a number of ethical dilemmas, some anticipated and some not, which are discussed in more detail below.

In the cultural context of conducting research in Saudi Arabia, giving written consent is a highly unusual occurrence, often creating marked levels of discomfort outside the clinical setting and in direct contrast to research conducted in Western contexts. In the approved ethics application it was stated that written informed consent would be sought, where possible, however, it was anticipated that this may not be culturally appropriate, and if refused, then verbal consent would be sought before proceeding with the data collection.

When attempting to seek written consent, many of the mothers commented, for example as Umm Saad did *"I do not need the information sheet or the consent form, they mean nothing to me. You will tell me everything I need to know when I ask you, trust does not need a signature"*. Umm Sultan said *"You are explaining to me everything verbally, so why do we need papers and signatures, I trust you enough, that's why I invite you to my house, besides, I will share my life with you not with these papers?"*. Another response from umm Hamad: *"We are Saudi or did you forget who we are? we understand each other and know each other by our families' names, so no need for these Western forms"*. Um Sarah said *"I am assuming you know how things work here, we are not in the US"*. Umm Sami reproached the idea saying *"Do you think when I decided to open my door to you and let you in in such very private and delicate matters of my life that I do not usually share with others or even with family members, that these forms would mean anything to me?, maybe you have been westernized"*. All mothers refused to sign the consent forms and showed

discomfort from discussing the idea and preferred to be told everything verbally.

Therefore, in order to be sensitive to the Saudi mothers and to balance the cultural context of conducting research in Saudi Arabia with the rigours appropriately required for conducting research in a western setting, verbal consensual agreement was sought from all the mothers. If insisting on their signatures, mothers might perceive disproportionate sense of seriousness, and be taken aback as result. Consequently, in all my interviews, I ensured to ask each mother regarding her consent in participating in the research verbally and this was recorded at the beginning of each audio recording of the interview and included in the transcripts of the interviews.

This issue is not without precedent when it comes to conducting research in Saudi Arabia. Al-Solaim (2009), conducted her research in Saudi in a hospital setting and mentioned that that verbal consent was deemed sufficient after consulting with authorities in the hospital and with colleagues who work in mental health profession. Al-Solaim explained that presenting the forms and demanding a written consent was likely to be counterproductive in a society where forms as such are rarely used. In a study by Honan, Hamid, Alhamdan, Phommalangsy & Lingard (2012) were they discussed the gap between theoretical expectations of research ethics as outlined in the many process ascribed to Western University Ethics Committees with the situated realities of researchers undertaking studies within their own sociocultural context. One of the authors of the article

Alhamdan, was a Saudi male researcher, who confronted the same issue of consenting his participants. He explained the difficulties around obtaining written consent in the field of education in Saudi, and how he ended up obtaining verbal consents from his participants due to the differences and practicalities associated with conducting research in Saudi culture (see Honan et al., 2012 for a review).

In this final section, I will take the opportunity to reflect father on some of the issues and challenges which arose in trying this study. In particular, I will be reflecting on my role as a Saudi researcher/woman and how directors, teachers, staff and mothers identified me and identified with me. In addition, I will be reflecting on how important it is to be represented in Saudi by someone mutual who knows both sides (e.g., between myself, the centres directors and the mothers).

Reflections

My role as a Saudi researcher

Some of the mothers participating in this research may have recognised me and accepted me as a member of a lineage they knew from other mutual families or friends. However, for most of those involved in this study, I remained primarily a Saudi woman who is known to many as the daughter of, a sister of or a friend of a friend, which is fundamental in trusting me to let me in their families' lives.

Being introduced by someone known to these mothers and being a Saudi were two fundamental aspects in trusting me and letting me in on their family's stories, details and secrets. So, it was the social and personal connection what really mattered for these mothers first and foremost, not the research topic or method. These connections helped them to build trust towards me as a person whom they associated with family members, friends or colleagues. In such a culture, an individual, be it a man or a woman, is deeply rooted in the aila (family) (Altorki,1988). Altorki (1988) also emphasised that to a great degree, one's status is attributed to and recognised by the status of the aila. This very important aspect of the Saudi culture is what yielded the opportunity to be in contact with different sites and more importantly with Saudi mothers of children with autism.

This was especially important as several colleagues and directors who work in the field had shared their concerns and doubts about Saudi mothers' who would agree and allocate the time to be interviewed for a couple of hours, let alone welcoming me (a stranger) in their homes as another alternative place for the interview. Also, many of them raised their eyebrows over the idea of me going alone to a stranger's house even for research purposes. One colleague said "*are you serious? Going to the houses of people you don't know! What if something happened there!*". Another commented "*maybe you forget our culture, so I will remind you that we don't receive people that we don't know in our homes, mothers won't feel comfortable doing so*". One comment which particularly struck me was when one of the directors said "*would your family allow you to go to people you*

don't know and go in to their homes by yourself?". Her comment reminded me that I had not as yet discussed this matter with my own family.

While I was not 100% convinced by their disapproval and worries, I also understood their positions and concerns. Saudi people generally welcome to their houses only the people they know. In a recent research study which was conducted in two different cities in SA by a female Saudi researcher who implemented qualitative research interviews with parents of children with disabilities, Alariefy, (2016) explained that neutral or public places such as schools and public areas (i.e., coffee shop or restaurant) were the choice to interview the mothers in her study. She indicated that such a decision was made to avoid conducting interviews in the houses of the participants, in which she would be considered a stranger. In this respect, a stranger should not enter a home and when they do, cultural attitude and customs might result in the host giving priority to show hospitality to the researcher over the interview (Alariefy, 2016). Therefore, going to participants' houses (mothers and families I do not know) as a researcher (stranger to them) to sit with them and ask them questions is certainly not a common practice in Saudi culture nor an easy process for either of us.

Privacy and Confidentiality

Two aspects played a significant role and encouraged me to seek help from professional transcribers without jeopardising the identity of my participants. First, all mothers in the study did not reveal their first name and

also intentionally guarded their own family's last name including the child's last name. By doing so, they were 100% sure that I would not be able to know who they are, link them to a family or a tribe and reveal their secret by linking their family name to a child with disability.

As discussed earlier, most Saudi families still feel embarrassed about having a child with disability and it is not unusual that most of them kept this hidden from their extended families and friends. Having said that, some parents carefully decided on who to share this secret with and how open they would like to be about it. Also, they made sure to give me a gentle warning beforehand regarding the subject to avoid any surprises. One mother amongst my participants told me before I was getting ready to leave *"if I see you anywhere please don't mention that my son is autistic, publicly I say he is an ADHD child, you know how our culture treats and looks to these children"*. I replied by saying *"I understand"* and I continued *"I wouldn't say a word about our conversation as I explained earlier to you about the confidentiality"* she interrupted saying *"if I didn't trust you in the first place you wouldn't be in my house, this is a different matter"* then she laughed and changed the subject. Another mother told me *"I don't take him with us when we visit my in-laws, because my husband didn't tell his family and doesn't want them to know about it. I personally only told my mother, sister and my dearest who care about me and keep my secret save not people who wouldn't care and use it as an entertainment in their guest rooms"*. Her eyes filled with tears, but she forced her composure and told me with a clear

strength *“you are from this cultural and I am sure you know how judgmental it is when it comes to such a thing”*.

Secondly, all the mothers have chosen to be called by Umm (the mother of not the eldest son as traditionally accepted), but instead they replaced it with their child with autism name, consequently they created another identity for them and added another layer of protection when they were with me. I was not aware of that until I interviewed a couple of mothers when Umm Faisal was then called by someone in the house by Umm Mohammad and she went inside to attend to them then came back. Even being a Saudi myself I was not aware nor expecting such an action. When she came back probably wanted to clear the confusion and then said *“sorry to interrupt our conversation, that was my husband calling me to tell me something before he leaves the house, he called me by my eldest son name, but I would like you to call me by Umm Faisal since we are talking about him”*. I replied *“whatever makes you comfortable”* and picked up where we left off. Only then I started to notice the same pattern with almost all of them.

In brief, all the mothers were protected by the way they personally choose to introduce themselves to me, that said by attaching their child with autism name to theirs instead of their eldest son name which make it really hard for anyone to identify who they are. Besides, they never reveal their first name and their family name which had secured and concealed their identity from anyone even the researcher.

Additionally, in the study their last name was not required as it was not of significance. Even in instances when the mothers showed me their child's diagnostic report, I noticed that they usually covered his/her name. Only two mothers decided to tell me their full names, but not the child's full name.

In conclusion, this study used an ethnographic approach to obtain data from a purposive sample of Saudi mothers of children with autism. Two qualitative approaches were used; participant observation and one-to-one in-depth interviews. Both were analysed using thematic analysis to provide an in-depth and thick description of the mothers' experiences.

Two centres specialising in the treatment of autism and 23 individual mothers took part from the city of Riyadh. Riyadh was selected because it is the capital of Saudi Arabia and where most of the services for children with autism are available. My family comes from Riyadh, so that helped to enable access to participants and overcome practical hurdles such as travelling to meet participants to take part in the research.

This study raised important ethical issues, in particular the issue of trying to obtain written consent, which proved not to be culturally appropriate or achievable within the sensitive context of Saudi. This chapter has also discussed different validity checks which are intended to account for the trustworthiness of the research, but also how they may be limited in the cultural context of Muslim countries such as Saudi.

Chapter 5: Results – Mother’s unfinished journey

In this part of the thesis, I will discuss the key results of the study in three chapters. Respectively, these three main theme-led chapters are 1) the invisibility of autism within the wider society and the difficulties of getting and dealing with a diagnosis; 2) the accounts of causality regarding autism and the explanatory frameworks used by mothers to understand the condition; and 3) the various stigmas (both internalised and external) associated with autism and the relationship of the condition to disability and disablement. Findings from both participant observation fieldnotes and in-depth interviews are merged and presented together to elucidate how mothers experienced and coped with bringing up a child with ASD in Saudi Arabia. In the discussion following, I will then return to issues which transcend the component parts of the results and have implications for understanding the research question in its entirety.

Thematic data analysis showed that mothers’ responses and behaviours clustered/grouped around particular themes. All themes generated were inductive and based on common responses and explanations offered by mothers to the interview questions and themes generated from the participant observation fieldnotes.

After completing the coding process for both sources of data, three major themes with sub-themes emerged from the data. *Mothers’ Unfinished*

journey, is the overarching global theme which transcended all the narratives and observations and within which the three major themes and sub-themes are grouped. These major themes (*Autism invisibility within the wider society and the difficulties of getting and dealing with the diagnosis; Autism causality and the explanatory frameworks used by mothers to understand the condition; Various internalised and externalised stigmas associated with autism and the relationship of the condition to disability and disablement*) and their connected sub-themes will be described, explained and outlined in these chapters and will be supported by extracts from the interview transcripts and participant observation fieldnotes. These themes and their interrelationship are outlined in Table 2, below.

Table 2: Results themes

Global Themes	Main Themes	Sub-Themes
Mother's Unfinished Journey	5.1 Autism Invisibility within the Wider Society and the Difficulties of Getting and Dealing with the Diagnosis	<ul style="list-style-type: none"> – Recognition and Realisation Process – Feeling Alone: Role of Mothers and Fathers During the Unfinished Journey – Isolation, Exclusion and Invisibility of Children with Autism and Their Mothers – A Culture of Conflict and Tension Between Teachers and Staff Towards Mothers and Vice Versa – Living with Autism – The Impact on the Wider Family – Challenges for the Mothers' Wellbeing – Mothers' Anxieties for their Child's Future
	5.2 Autism Causality and the Explanatory Frameworks Used by Mothers to Understand the Condition	<ul style="list-style-type: none"> – Causes of Autism: Mothers' Perceptions – Giving Meaning to Autism – Cultural and Societal Beliefs in Response to Autism Onset and Diagnosis – Transitional Experiences of Autism Diagnosis – Changes in Mothers' Character – Advocacy, Activism and Religious Growth and Enlightenment
	5.3 Various Internalised and Externalised Stigmas Associated with Autism and the Relationship of the Condition to Disability and Disablement	<ul style="list-style-type: none"> – Stigma: Negotiation, Language and Communication

Global Theme: Mothers' Unfinished Journey-Path

The common description or narrative used to describe the experience of autism within the mother's accounts was that of an "unfinished" (*rehla*) journey or (*darb-tariq*) path. Both these phrases were repetitively and interchangeably used by mothers from a range of backgrounds included in my sample, and were prevalent throughout their discourses explaining their personal stories of encountering and dealing with (*tawahod*) autism. For example, one of the mothers said "*this (rehla) journey will take forever, it won't end no matter what I do*". Another explained "*I feel no end to this (tariq) path, whatever we do he is not changing, so we need to walk that (tariq) path until the end*". In a very wretched note Umm Sami said "*I know I won't be able to walk with him all the time in this difficult (tariq) path, I continuously worry about what he will do when I die*". Umm Hamad explained "*it feels this (tariq) path is going to have many different (mahatat) stations, can you believe that some of the past ones I can't recall how I felt or what was going on, anyway, Allah yeyaser al (darb) path (God will ease the path)*".

5.1 Autism invisibility within the wider society and the difficulties of getting and dealing with the diagnosis

Recognition and Realisation Process:

This is the very starting point of the journey for all mothers. This stage represented the start of mothers' journeys in which all of them noticed unusual and unexplained behaviour displayed by their child. They also recalled various medical issues which affected the child's health from birth, as well as some other complexities. Mothers described differing levels of concerns and uncertainties during this process. In common was the realisation that their child did not behave in a manner typical of other normal children but not understanding why. Umm Hamad recalled:

I noticed he doesn't talk at all, he is very quiet unlike his eldest brother, it was very strange, so I decided to search the internet about the nontalkative child and (tawahod) autism popped up, I ignored it because it wasn't in my mind at all. Also, I noticed that when my mother asks him to close the door or to turn off the light he doesn't complete any order even the smallest one, he doesn't even look at her when she talks to him. He doesn't complete any task like children his age would do. He was around two years and three months, and should be able to complete such a task. Do you know I don't recall that period very well it feels like a dark time, complete darkness, do you understand me? I don't even remember my feelings and how I felt through that period it just felt a total darkness....(a deep and long sigh heard).

Umm Saad described this process:

Since he was born he had many health issues (e.g., he doesn't sleep well but his eye contact was ok, he vomits his milk all the time, every week he would have diarrhoea for days and was on antibiotics for months), but still not enough to think of the unthinkable, I guess my awareness was so limited that time. At two years and three months he stopped calling us mama and baba, and all of a sudden, he started flapping his hands and became hyperactive with no eye contact whatsoever, his eyes fixed towards the floor for 24 hours a day. It was like he got into another world. With all of that, obviously I was

disturbed and bewildered yet I didn't get what was exactly going on with him, I kept asking myself what is wrong with my boy but couldn't figure out what it was. Something wrong with him but what is it? For example, the minute he gets up from his sleep he would look through the window and start laughing hysterically nonstop, it was so weird. I was thinking maybe he was possessed with jinn. Our maid told me that he always laughs hysterically the minute he gets up in the middle of the night even before turning the light on. If I leave him alone for a few minutes I would come to find water running in all the taps around the house, spices and sugar spread all over the kitchen floor. He does weird things and plays weirdly with anything, he is not like his eldest brother. He glues his eyes to the red line which was running with the news at the bottom of TV, that's how he watches TV. My mother used to say that something was not normal with this boy, but I wouldn't think of (tawahod) autism simply because at that time I have never heard of such a word or even knew what it meant.

Umm Sami recalled the process by saying that:

When he was three years old we left him with my mother and I travelled with my eldest daughter and husband. He was hyperactive and moved really fast, so I was worried he might get lost or run to the street and something would happen to him while abroad. I was just really annoyed by his nonstop movements and that's all, never have thought of tawahod autism or considered any special needs issue. I just thought that being a boy is different than a girl, so that's why he's acting that way and will grow out of it. Besides, at that time my motherly protective side excluded any illnesses or any impediments, you know as a mother you never want to think of the unthinkable or such a possibility besides, it won't even cross your mind, Allah inshallah won't allow such a thing to happen. When we came back from our travels, my mother told me that when calling him, he never responds to her or his name. She noticed that he doesn't even recognize his name. I had never noticed these issues, probably because I used to provide and do everything even before he asked for it. I thought he was fine, but after what my mother shared with me, I noticed too that he doesn't respond to his name at all. So, we decided to check with a doctor. We took him to the hospital and was seen by a visiting doctor from abroad. He told us he is autistic, we had never heard of such a thing, so I asked him what kind of medication he needs or does he need surgery for autism. This was some twenty five years ago, as you can imagine few knew about autism at that time? He said he doesn't need surgery or medication. All he needs is for you to get closer to him, show him love and play with him.

Umm Sami's eyes were full of tears and she struggled to continue her story and suddenly avoided looking at me and looked to the opposite

direction. Umm Adal also recalled that time with noticeable distress, typical of many of the mothers' narratives, but she clearly was not comfortable and something else was irritating her. She said:

Tawahod is a catastrophe, at the beginning I couldn't take it nor accept it, now it's been five years and I'm struggling to comprehend or endure it.

She stopped and covered her face with her two hands trying to fight her tears and the obvious pain. She then looked at me and said “do you want to listen to such pain? Why would you want to hear my sadness and my misery?” I replied only if you feel ok to continue and talk about it, otherwise, feel free to stop and I can leave? Before getting the chance to explain any further, she slowly nodded her head and looked away towards the other direction of the (*majlis*) guestroom door. She went up and closed the door then came back to where she was sitting and continued.

I really try hard to show my power and strength especially to my eldest daughter, I don't want her to feel my vulnerability and sorrow towards Adal, I always try to show her that I am enjoying every bit of him, deep inside I feel I'm hardly breathing, I feel DEAD. When I go out I feel I'm dead I am not who I used to be, I'm another person. Deep inside everything has stopped in my life, life has become tasteless. I just pretend I'm happy but if you look inside me all I want is to stay home and close my door. Since he was two years old, I felt deeply that he is not normal. Walking on his toes never on his feet, speech delay, super active, his hyperactivity was so obvious since he was a year and a half, he never managed to stay in one place for a second, he is not a normal boy or like normal children. So, I took him to a psychiatrist to be checked and the psychiatrist said “he is really abnormal and too hyperactive for his age and thought he had another problem but didn't know exactly what”. The paediatrician didn't provide me with an answer regarding his tiptoeing and told me “he never saw a child like him”. By three years old somehow deep inside I started to believe that he is definitely not normal.

Umm Mohammad recalled that:

He wasn't like his brothers. He didn't sit until he was a year old and didn't talk until he was two years old. He started to show weird behaviour such as; flapping his hand, which I found strange. Also, when he is upset or feeling angry he bangs his head on the walls. I found this bizarre and scary. I was so so worried and concerned about him and couldn't understand why he was behaving so weirdly, yet no one supported me to go ahead and check what was wrong with him.

Umm Hamid told me her story by saying that:

I didn't notice anything was wrong with him until my mother told me that my son isn't responding to others when they call his name or to anything around him (e.g., sounds or movements), so she said something is going on. You see he was my first child and the only one, so I wasn't able to tell the difference. Besides, I live with my mother-in-law and have to do all the house work and the cooking alone without any help, so that didn't help me to see how my son was doing. But after my mother's comments, I started to notice things by myself. For example, when I call him, he didn't respond or even look at me. He doesn't smile or laugh when I tickle him like normal children do. All he does is watch TV, actually glued to TV all day long nonstop and he doesn't even move.

All of the mothers passed through a gradual process of recognition and realisation, some realising for themselves, others being told by their own mothers (maternal grandmothers) that their child did not behave in a manner typical of other normal children or typical of their siblings. They started from feeling something was wrong to feeling more concern regarding their children's unavoidable and strange behaviours with no reasonable explanation. Whilst noticing something was wrong with the child, most mothers displayed scarce knowledge about ASD and its existence, no matter how educated they were. In addition, most of mothers showed some internal resistance to really wanting to find out what was going on with the child.

Throughout their deep and detailed narratives, most mothers reluctantly shared that they really did not want to admit that something was

not right and hoped it would disappear or change at some point. For example, even when autism popped up in her internet search for her son's strange behaviours, Umm Hammad had decided to ignore the word "*I ignored that word, I didn't like it, so I close my eyes and deleted everything from my mind and moved on.*" She continued "*Do you know I don't recall that period very well it feels like a dark time, complete darkness, do you understand me? I don't even remember my feelings and how I felt through that period it just felt a total darkness....(a deep and long sigh heard)*". Umm Sami explained that "*I was just really annoyed by his nonstop movements and that's all, never have thought of tawahod autism or considered any special needs issue. I just thought that being a boy is different than a girl, so that's why he's acting that way and will grow out of it. Besides, at that time my motherly protective side excluded any illnesses or any impediments, you know as a mother you never want to think of the unthinkable or such a possibility besides, it won't even cross your mind, Allah inshallah won't allow such a thing to happen*". Umm Saad, explained that autism was an unknown thing/condition to her and her family before her son's diagnosis.

In sum, an inner denial was a factor shared by all mothers throughout their narratives as they realized that something serious was going on with their child. Interestingly, in their narratives some mothers who had a slight knowledge about autism showed particular resistance to the word "autism" when, for example, it came up in internet searches. As Umm Hammad said "*I hate that word and still do*".

Feeling Alone: Role of Mothers and Fathers During the

Unfinished Journey:

Some mothers' doubts towards their children's unusual behaviours were validated by their own mothers (maternal grandmothers), but most noted a lack of validation and support with their concerns, whether from their husbands or their own mothers. Almost all of the mothers described some anger and frustration towards the fathers, who they considered to be taking an unsupportive role concerning their child's strange and unexplainable behaviours. For example, some fathers were described as assuming a passive role and "turning a blind eye", leaving the mothers to deal with it alone. Others forbid mothers from taking the child to obtain a diagnosis, or cautioned the mothers against talking about the child's strange behaviours with anyone, even their own family. Thus, most mothers felt that they were left alone, and describe this time as marked by extreme loneliness, despair and exhaustion.

Umm Madawi recalled:

For the first two years and a half nobody knew anything literally anything about my daughter and her weird behaviour and issues except only my mother. My husband's family didn't know anything about her until things were resolved with my husband. For the first three years of her life my husband distanced himself and didn't support me at all in anything concerning our daughter. He used to say to me "let doctors play up with your mind and take you money, there is nothing wrong with her, it is all in your crazy head". He didn't go to any appointment nor even help with paying the fees. I was alone so alone, distressed and confused. It was a horrible period of my life, I badly suffered by handling all of it alone. Leading two different lives wasn't fun either. One was for the outside world which was the rosy life-a perfect family with the perfect-normal child who has purposely kept hidden from the world, while my other real life is destroyed and I was on the verge of suicide, yet my husband didn't even care.

Umm Mohammad's recollection of the event was very similar to the above, however she had to wait longer to get a diagnosis of her child after going against her husband's refusal and the rest of the families' denial of what was obvious to her.

I felt my son wasn't normal from the very beginning. He was so different from his brothers it was so obvious, yet his father who works in the medical field was reassuring me that he was normal and said to me "don't ruin his reputation and future by talking about him, he will grow out of all that and will be fine". Even our families were saying "he is ok and nothing is wrong with him, they think I am the one who is having issues". Who am I supposed to believe? my own eyes? or the answers I found on the internet about his abnormal behaviour? It was extremely tough, but at the end I did what felt right and ignored them all including his father. Though it took five years to get there. It is really tough when all of your family is against your opinion. And by the way, I wasn't allowed to take him to the hospital where his father work and still we can't go near that hospital.

Umm Tareq explained her own struggle with her husband by saying:

I had two children before him, so it was easy to spot and feel he was different from them. Every time I talked to my husband about his unusual behaviour his replies "you are over concerned or you are obsessed" and he rejected my suggestion to take him to a doctor, but I took him myself to two different doctors and I was told there was nothing wrong with him. I didn't believe them, however I didn't know what to do or where to go. Then my uncle saw him once and I told him about his issues and behaviour, so he told me where I should go to seek help. If it was up to my husband, he would have kept him in the house behind closed doors and that's that.

Umm Hamid told me her story by saying that:

When I told his father about my own observations on our own son's unusual behaviours such as; not responding to his name or looking back at me when I call him, yet he is three years old, my husband replied back saying "he is ok and he will talk latter" my mother-in-law said "this is rubbish and nothing wrong with her grandchild at all, he will talk latter, he is still little and said his father didn't talk until he was four years old", so I shouldn't make a fuss. I couldn't do anything even taking him to a doctor because I don't work so I don't have money and my husband wouldn't agree on taking him to a clinic to be seen and checked.

Umm Saad said:

My husband literally used to menacingly warn me and prevent me from saying anything about our son even to my own mother and his explanation was that “he is still too little and all these weird behaviours I see will disappear when he grows up and he will be normal like his brother”. He also used to tell me that “talking about these behaviours will ruin our child’s future and reputation, because all these behaviours will go away”. I was so confused and probably believed him for a while or deeply wished that will eventually happen, but it didn’t.

Umm Ali said:

My husband used to say “there is nothing wrong with him, he will grow out of that, it is you who imagined things”, I wasn’t, I believe it was so hard on him to believe or even to accept that his son is not normal. I quarrelled a lot with my husband because he was refusing the idea of taking him to hospital to be checked up. I had many serious fights until he allowed me to take him to a hospital.

From the above it can be seen that most of the mothers had experienced different kind of struggles with their husbands and/or their families, compounding feelings of loneliness in their unfinished journey in regards to their children’s unusual behaviours.

Collectively, all mothers experienced significant resistance by most of the fathers towards diagnosis or the idea of finding answers, regardless of the fathers’ educational background. Some fathers went as far as banning the mother from discussing any of the child’s unusual behaviours with others including the father’s family. For a few years, some mothers followed their husbands’ instructions for keeping their worries and observations about the child buried and hidden from anyone including their own families. The main themes of the Fathers’ resistance discussed by the mothers could be constructed around: the child will grow out of this, talking about the child’s behaviours could damage his reputation forever, mothers’ ideas and

observations of the child being unreliable, exaggerated and reflecting the mother's manic obsessions about the child, and shame. Even when a few of the fathers gave their permission for a diagnosis to be sought, the mothers, for example, were not allowed to go to the same hospital where the fathers worked either as a medical doctor or a hospital employee. In addition, some fathers did not financially contribute to any medical expenses and left the mother solely to deal with the financial burden until they were ready to join the mothers through this journey.

From the above it can be seen that fathers demonstrated their own methods of denial of the child's issues. A few fathers even went as far as seeking divorce, so they did not have to be involved or present during any medical appointments or accepting autism as a diagnosis. Umm Salah explained the situation as the following *"the continuous disagreement between the two of us about the best way to get our son a diagnosis and to deal with autism was to get a divorce. For several years I was blindly following his decision of not seeking diagnosis because for him our son is normal and I am the one who is crazy. And when he agreed to let me go to seek help he didn't accept autism and believed the doctor is not qualified. After two different diagnosis in two different hospitals the decision was he is out of this because he still doesn't believe in autism and if we to stay together I am not allowed to do anything to my son, so I had to choose separation to help my son. We have different ways of dealing with this matter and I didn't have any other choice"*. Fathers' worries about their own reputation and their families' reputations being damaged by having a child

with autism were revealed throughout the various stages of mothers' recognition and realisation. Um Hamid for example was not allowed to take her son to be seen by a doctor and was only able to do so after her divorce.

The above two themes (recognition and realisation process and feeling alone) highlighted a culture of invisibility for the child with special needs within Saudi culture, which was maintained by the families of these children and continued throughout some of the established educational organization/schools for autism. The next theme will discuss that matter.

Isolation, exclusion and invisibility of children with autism and their mothers:

This theme describes how children with autism were positioned within the organisation they attended on a daily basis and how they were perceived by the professionals working with them. While all the staff in both sites agreed that autism in the Saudi Arabia is understudied and a lot still has to be done, the following incident illustrated how children with autism and their families remained invisible and concealed. Everything was made for them and everyone talks about them, yet they remained unseen.

I was told on one occasion that the director of the first site service wanted to see me in her office. Once there, in a very excited tone the director says "*tomorrow we are having a celebration event for atfal altawahod (autistic children), I want to make sure you are coming, all executives' bosses will attend to see our progress and what we have done so far*". I was surprised because I have not heard any of the teachers or staff talking or

mentioning anything about this. They usually talked about many different things during the day but not this. I told her *"of course I will come"* then I asked her *"if she wanted me to do or help with anything"* she replied *"nothing really, you have been of great help, so I want you to come to enjoy the event and mingle with the big bosses, some of which you have worked with years ago"*. So the next day I arrived and was escorted with the director and another two members of staff to the event. This took place in a very large building with many scattered buildings attached to each other by secured entrance and exits doors. Next to each inside door that connected one building to another was a female guard to open and lock the door. I had never managed to navigate them by myself. The director said *"we are almost there"*. A big door opened with a short corridor which led us to a huge auditorium; I was really astonished. I did not imagine such a professional theatre would exist. Everything was arranged perfectly with a luxury generous canapés table on the side. There were a couple of ladies who's job was to serve Saudi coffee and tea to everyone. After we were served coffee, the director started to introduce me to other directors. A number of women arrived where the director went immediately to receive them and walked with them to their reserved front seats. I recognized a couple of them due to my previous work and different activities in the field. Overall very few people were occupying such a large theater. I looked around to check on the teachers and the children, but no one was there. I was thinking that they must be getting ready behind the stage and the huge curtain to start soon. I also noticed that none of the mothers of autistic children were there too. I thought they might be late as transportation can be an issue in Saudi. I

realized also that the timing of such a celebration was not great or convenient to parents in general. It started at the end of the school day when parents would be going to pick up their children. While all those ideas were going through my mind, the director appeared on stage welcoming and thanking all those in attendance then introduced the upcoming program. A student with moderate intellectual disability from the neighboring building started the event by reading verses of the Quran. A group of children who were only physically impaired performed the Saudi anthem. Then one teacher gave a PowerPoint presentation about autism (i.e., its definition, characteristics, prevalence and gender ratio). There was then another performance delivered by a beautiful group of girls and boys between the age of eight and twelve years. This time the children who were physically impaired and using wheelchairs were shielded behind the children with intellectual disabilities with no perceptible physical impairment. Then one of the executives went on stage thanking all the efforts of the participants and in particular acknowledging all the changes witnessed to improve, support and change autism in the country. The celebration then ended. Not a single child with autism was there.

The director came towards me with a big smile asking “*what do you think of our event?*”. Then without waiting for my response she continued “*let’s go to our day care center the big boss is coming and wants to talk with you*” “*I nodded*”. When we went up and the door to the day care centre for autism opened, I saw a group of mothers with their children kept in the waiting area with some toys. One of them said “*how was the event?*”. I was

very embarrassed and annoyed, I could not look her in the eyes. The other mother was asking me “*do autistic event look like this in America*”. Before even trying to think of a word, the director came and quickly said “*I am going to take doctor Taghrif for a meeting and you will meet her another day*”.

The meeting that immediately followed the event was with one of the government executives chief for autism; she only thanked the teachers and the director for their obvious hard work with children with autism and their challenging behaviours, but without discussing or questioning the absence of these children in the event. She also praised the event, the great arrangement and the children’s performance. This was considered a “celebration event” for children with autism and the progress made in the field of autism; but without these children nor their mothers present. It was not just the children with autism who were invisible in this event, their mothers as well felt excluded. I got a couple of calls from two mothers of two autistic children registered in the school asking me different questions about the event. One mother said “*what did the event look like?*” “*who was there?*” “*what did they say about autism?*”. I replied to all of her questions, but her disappointment could be felt and heard throughout our one-hour call.

The other mother Umm Hashem asked me “*why we are not invited?*” “*aren’t they our children?*” “*I want to know what do you think of it?*”. In our discussion I was aware of her anger and discontent. To say the least, I was deeply upset and really irritated by the event myself but I was aware of my position and my limitations. I replied to her questions by saying that “*while I was invited to the event, I don’t have the right to say my opinion, unless I*

was asked, even though I believe it can be managed differently". I also, said "I am not an employee, I am just a researcher who is visiting and working with them for a couple of months" she interrupted saying "I know that, but you are studying in the West so you have new and better ideas for tawahod, I check about tawahod in the US and the UK via the internet, why don't they use what you know?". I replied "I am sure they will in the future" and I continued saying that "I really understand your frustration and sadness and I would like to assure you that once I have the chance I will tell them my views on that event". Silence filled the call then she cleared her throat saying "nothing new, we and our children are always disadvantaged" she continued "don't get me wrong, but even with your research nothing will change" she continued to stop me from talking and said "anyway, sorry to throw this at you, I feel I can trust you and I'm sure all of this will be between the two of us" I immediately replied "without a doubt", then I thanked her for trusting me and confided in me. She ended her call by saying "I think you should go and told the director your view about the event and never wait for the chance, because you are our voice as well as our children, you are an expert from the West and they will listen". I said "I will try my best", then she said "I will find a good day and I will invite you to my house to interview me" I said "whenever you are ready just let me know". I never heard back.

The sense of invisibility and exclusion of the children with autism was not limited to this event. Whilst in the above-noted example, these two mothers were upset to have been excluded from this event, I noted how this was also exhibited by most of the mothers I met with. In nearly all cases, the

mothers of the autistic children limited and controlled my access to their children. Some might just show me a photo of the child, a video or both, while the child stayed in the next room. Others might just let the child join for a couple of minutes before asking him/her to leave. What was collectively common from all of these mothers, was that one question I got every time after they swiftly introduced their child to me either in person or in a picture. *“Did you see he looks normal right? not like others autistic children you have seen”*. *“She looks like other children you can’t tell it is tawahod, right!”*. *“He is like other children can you spot a difference? And people wouldn’t know unless you say the word tawahod”*. *“Tell me what do you see? Nothing that different from other children!”*.

On another occasion, I was invited by one mother to attend, together with some other mothers, a farm that they would visit with their children. I asked her the reason for the invitation and the idea behind a farm. She replied that *“every month the six of us get together with all of our children and go to a farm where the children with autism in particular can play freely and away from people’s negative comments and weird staring...etc”*. She also said *“it is a nice time for us as mothers to feel free and treat ourselves to a nice dinner and conversation away from autism or being alerted 24/7 like in public places, where our autistic children are mostly unwelcomed”*, before I answered she continued *“we all really trust you, so we feel ok to welcome you in our circle”*. I thanked her and told her *“I’m really honoured to be trusted and invited by all of you”* and asked her about the details and the arrangements, as well as the day and time. The day came and I went to

Umm Hani's house. Umm Hani came to me in my car and said "*why don't you come with me in my car and let your driver follow us, so we can chat through the trip*", I agreed. I went to her car where Umm Nabeel was there fully covered, although her face was not. I myself was fully covered like Umm Nabeel, although my face remained uncovered, and another fully veiled mother was sat quietly next to her. We greeted each other and I joined them. In the minivan there were eight children, two maids and Umm Salem fully covered including her face; I waved to her with my hand and she waved back. There was a third car with Umm Mishaal fully veiled with her *Niqab*, where it leaves only the eyes uncovered, a teenager boy, Umm Jassir in her *Niqab* and a maid. All of us combined represented the most common spectrum of Saudi veiling.

It took us around forty-five minutes to reach the farm, which was located in a small town to the northwest of Riyadh city. We approached the highly walled and gated farm where all the cars drove through the big gate. We got out of the car and the drivers drove all the cars out to the other separated side of the farm. Umm Hani welcomed all of us to a very huge *Majlis* (guest room) and all of us took off our Abaya and started to get comfortable. To my ultimate surprise, the fully covered and quiet mother turned out to be a mother I had interviewed previously in her house. I followed her lead and did not acknowledge her, or our prior meeting. Umm Hani introduced me to her then introduced her as "*this is Umm Huda who didn't join us last time*", so we both acted like strangers who were meeting for the first time. All of us started to make our way to a corner of the grandiose

Majlis where a table full of Saudi coffee, dates and different kind of desserts were ready and arranged for us. Some of their children with normal development kept coming back and forth talking, asking for different things from their mothers. Most of them introduced them to me and told me about their order between their siblings. However, their children with autism were kept away with two maids looking after them and the only two who joined us in the *Majlis* for a couple of minutes were not introduced to me, instead I guessed because each one approached his own mother. I did not ask because it was obvious that my inclusion within their circle had specific roles, which is to maintain certain boundaries but never cross them. We spend around 6 hours there from 1pm until 7pm and most of their discussion centred around autism. I joined them for another four visits to the farm with almost identical patterns. Umm Huda continued to be invisible to the group and to me; she never told them about our interview nor tried to open any conversation with me or the group, and she was quiet most of the time. The group also was very nice to me and involved me with their monthly meeting until October 2014, but they maintained their invisibility by not individually participating in the research or introducing their children with autism to me.

From the above, it can be seen that mothers and children with autism were invisible and excluded, even from a special event tailored for autism, but also that these mothers routinely excluded their children from meeting me and kept themselves and their children invisible.

*A culture of conflict and tension between teachers and staff
towards mothers and vice versa:*

This theme captures the ongoing conflicts and tensions between the teachers and staff towards the mothers and the reasons behind such a conflict. There were also further tensions and conflicts between mothers at different stages of their journey of bringing up a child with autism. These issues are discussed next using excerpts to illustrate these conflicts and show their dimensions.

During my work in the first site where there were classrooms for teaching and supporting children with autism, I heard almost from the first week various complaints and criticisms expressed by staff about the mothers. One member of staff said “*the mothers of tawahod (autistic) children are so demanding and spoiled*”. Another replied saying “*they want us to change everything about tawahod without getting involved*”. One teacher told me that ‘*two mothers in particular are too demanding, useless and do nothing with their children*’. She continued saying “*you will see yourself the pressure and all the work we do with the children, you know how hard working with these children is, yet the mothers are always uncooperative and ungrateful*”. One director mentioned to me that she has to be tough with mothers most of the time, so that they can work with their children when they go back home. She said “*I told the mothers that my teachers are the best and they are tired and stressed from working with your children while you are lazy and doing nothing with them*” “*you know being a bit hard will encourage them to work and be grateful*”. The general idea held

by most of the teachers and the staff in one site towards mothers of children with autism seemed to be negative with rare attempts made to find out the issues affecting both sides or to remedy the situation.

On one occasion, I had just arrived at the site with one of the mothers and her 7 years old son who was disturbed, upset and crying nonstop. His teacher received them with direct criticisms and scolding. She said "*he always comes in crying and with bad mood, he disturbs the whole class, you should work with him, put him in bed early, don't give him the iPad*". She then took the iPad that he was carrying, at which point he started to scream and cry hysterically. Then she called the school's maid and asked her to take him to the classroom where an assistant was there with the other children. She did not give the mother any chance to say a word or even a few seconds to explain. The mother was embarrassed and speechless. She quietly said with obvious struggle "*I will do that, but the taxi is outside and I can't stay anymore, I am really sorry that my son causes lots of trouble*". I saw the mother coming out earlier from a rented taxi as we arrived to the school at the same time. I walked so quietly then the teacher said "*did you see what I have to deal with every morning?*". I nodded as I did not want to reply or to talk. I was shocked and devastated by the situation and needed some time just to calm down, simultaneously thinking of the mother's unpleasant and hostile situation. The teacher then asked "*why are you so quiet? You look sad is everything ok?*", I replied "yes". We parted at the end of the corridor as I needed to go to sign my attendance sheet and put my *Abaya* and stuff away.

One mother in this site told me during a parent-teacher meeting, which to the best of my knowledge was the only one meeting during my five months attendances that I was able to observe, that *“as a mother I feel exploited”*, in that every time she stepped into the school her son’s teacher started to complain nonstop. She continued *“autism makes you feel belittled and humiliated from your son’s behaviours, as everyone around complains about his behaviours the minute they see me”*. The only time I get into the meeting his teacher, the staff and almost everyone around started to say *“your son makes lots of troubles, your son is so violent, he hits us hard, he bites us ...etc, mothers don’t really need to hear such things, it’s hard enough on us, I really feel humiliated, but can’t go to another place, as I have no other choices”*.

Another mother told me *“it feels like a fate...an ill fate, no matter what you do, children with autism can’t be controlled, which upsets their teachers, in turn we get no help or direction offered by them or the school on how to deal with them!”*. I met with Umm Sami who’s son went to a private school, she said *“do you believe that his teacher beats him due to his constant movement!!, when I found that I couldn’t sleep and next day I took him to the school myself and showed his teacher the marks do you know what she said?”*, without waiting for my answer she continued *“your son is like a bomb and ready to explode anytime, and uncontrollable, so tell me what to do with him?”*, *“I couldn’t say a word and left the school crying and distressed, it is a very expensive school a private one, where we expected help and ideas to deal with him not to be hit with these harsh complaints”* *“I couldn’t do*

anything or move him to another school, you know most of the few schools/centres for autism require the child to be on the mild side and without any other disabilities or problems.” She cried so hard and showed me some pictures of him.

From my previous work with children with autism in SA and through my fieldwork in this study, it can be confirmed that both governmental and private schools/centres still require that the child with autism have to have mild autism with no other disabilities or complications to be accepted and registered. In turn, many children with moderate or severe autism with other disabilities stay at home or are sent to boarding schools/centres in Jordan, Kuwait or the UAE, with the continued issue of tension between teachers and mothers of autistic children.

Another conflict was observed at the other site where a couple of volunteer mothers of older autistic children worked, supporting and advising the mothers of newly diagnosed autistic children. This example demonstrates not only conflict between teachers and mothers, but also conflict between the mothers themselves. One of the volunteer mothers in the site always complained about the mothers of autistic children who were new to the centre, saying *“they are so spoiled, lazy and nothing is enough for them, when we were in their place years ago no one knows what autism was and we struggled to find any information? now we provided them with everything yet they aren’t grateful and they don’t want to work hard with their children”*. Another mother said *“they are so privileged compared to us years*

ago, but unfortunately they aren't seeing that, nor want to see it, it is easier to complain instead".

For a couple of new mothers who heard such comments, they were not happy and felt violated. In one of the mothers' meeting, one of the new mothers said *"I'm not privileged or lazy, it is so hard to see my son suffering from autism, besides while I really appreciate and so grateful for your constant support and help, I don't have to embrace your previous experience to show my gratitude"*. Her eyes were full of tears and she left the room. On another day at a meeting a different mother replied to such a comment by saying *"your son is around twenty years old, mine is just about 4 years old, so your comment wasn't fair or accepted, it took you twenty years, maybe less to accept autism, I'm still struggling with it, so I need my time"*. In general, most of the new mothers keep quiet and tried to get along with the support material, but their frustration and discomfort in regard to the way they were always perceived by some of these volunteered mothers could not be missed.

In another incident a volunteer mother who had seen me sitting with a new mother trying to comfort her told me later in another day that *"I should be firmer with them, as every day passed with no training for the child is a disaster"*. She also said *"I should tell them to be strong and fight hard for their children"*. I replied saying *"I don't feel I'm in a position to ask them to do so, nor do I believe that such a way could work for everyone!"*, I continued saying that *"different people need different time to cope with such an issue, besides their struggles will always be there, but I'm sure they will rise for the*

matter” and left it there. In one of my interview, on mother told me that “one of the reason stopped me from going for support and help in that site, was some of the staff way of advising and helping”, “I was just hit by his diagnosis at the age of five, I was lost and got zero information about autism, I knew about them via the internet, so I went for help the next day” “instead I got lectured about being weak and how time flies, so I have to work with him from tonight!!, I was freaked out, why would I want to hear about adults with autism!! or hear about a mother’s experience that happened twenty years ago?! no one would like to her this at the beginning of the diagnosis, so I left them and never went back”.

In conclusion, these two themes which emerged throughout my participant observation within and outside of two different specialist centres showed that isolation, exclusion and invisibility of the child with autism and the mother existed on a cultural level as well as within an institutional level. Also, negativity has been affecting both sides (teachers with mothers, and mothers with other mothers). The continued conflicts and tension between the old mothers and the new mothers appeared to be hindering the provision and acceptance of support and help and perpetuated all parties’ ongoing sense of isolation and exclusion.

Living with Autism:

This sub-theme looked into the mothers’ individual experiences of dealing with their responses to their children’s diagnosis of autism. Also, how they were navigating their own reactions overtime. Consequently, each

mother of a child with autism endures a unique different (*rehla*) journey in each stage they go through within their overall unfinished journey. Umm Saad said:

with tawahod every time I have a different long (rehla) journey, first to make his father see what is going on, then another rehla to convince him to seek medical help, and then the rehla to find a school...etc. probably we need to get used to different (rehat) journeys until our son is ok.

Umm Adel stated that:

Every stage of his life no matter how big or small it is, I know I'm going to start a new (tariq) path not just for him for me to prepare for the unknown.

Receiving the diagnosis of autism was experienced as an important step towards having answers to the mother's many questions, and to accessing services and support. Diagnosis was a life changing event, which could result in strong and varying emotional reactions for the parents. The degree to which mothers had processed and come to terms with the diagnosis varied. While some of these reactions had faded or settled, some still strongly lingered on within many mothers, even after many years had passed since the diagnosis. One mother (Umm Adal) said:

tawahod is a calamity, a calamity literally breaks my back. I just want to live through it, so he can get through, I have no choice but to live with tawahod

Umm Saleh explained her understanding of.

tawahod is a catastrophe, a catastrophe I find extremely hard to swallow and hard to comprehend, it's been five years since his diagnosis and I still find it hard to fathom, inside I'm dead, I pretend to be strong and ok with it in front of my family, I have no other option.

Umm Zayed stated that:

in the beginning tawahod was agonizing and a harsh reality, now I guess I get used to him and his unusual behaviour, but adjusting to tawahod is impossible no one would adapt to it”.

Umm Malik said

his diagnosis was the biggest shock of my life. I was crying all day long every day for a couple of months, and praying in the middle of the night every night asking Allah’s help and support with endless tears, it is tough and painful, but witnessing few changes in him make me feel a tiny bit okay and hope that he might improve, all is in Allah’s hands.

Umm Sultan reported that:

I am not accepting tawahod, but I always call upon Allah for support and guidance. I ask Allah to help me to accept my fate and be content with what Allah plans for me. I still get upset about tawahod, but then I would say that’s my fate.

Umm Tareq shared:

At the beginning I wasn’t convinced by tawahod nor accepted it, but my mother knows how to boost my spirit by reminding me that Allah has chosen me because I’m up for such a responsibility and that I can handle it, I feel happy hearing that. Also, when he improves with his training I feel I’m ok with tawahod.

Umm Mohammad put it:

First I needed to believe in myself, in turn it aids in boosting my confidence and helps me to accept myself then accept my child and his tawahod, of course at the beginning I needed to take antidepressant medication to help me and now I’m ok without it.

Umm Judi said:

as long as I know what she wants and doesn’t want, how can I comfort her and make her happy I’m ok with tawahod, otherwise tawahod is a dangerous and complicated illness to deal with.

From the above it can be concluded that the identification and the diagnosis of autism caused a significant emotional response among the mothers. All the mothers’ emotional responses were obvious during the

interviews no matter how hard they tried to compose themselves. Throughout the various narratives of recalling different events and feelings constructed around the experience of diagnosis, all mothers demonstrated continuous resistance to “*tawahad*” and a struggle to accept it. Even though they tried hard to show their general understanding of autism as a condition, in applying it to their reality they showed unending rebuttal and deep bitterness. The state of denial kept simultaneously running in the background of their minds all these years. While each mother endured a unique and individual journey of her own, this life changing event was the one theme which united all of these mothers in their different journeys.

Such an event would also pose and represent the entire family with many challenges. After the process of the identification and the diagnosis of autism all mothers were confronted with the task of adjusting to the positive and negative impacts of having such a child in the family. The next theme captures the experiences and attitudes of the mothers and other family members in living with autism.

Impact on the Mothers Versus the Wider Family:

All mothers voiced directly and indirectly that living with a child with autism had an enormous impact on the entire family although tremendous stress specifically on them. Society in Saudi is strongly male dominated where a father’s responsibility is mainly to provide the financial support for the family. The mother of the family is the one who takes on all the family

responsibilities with little or no help from the males of the family. Umm Adel said:

All the time I'm the only one handling him and dealing with all of his issues. His father is not involved. For example, he goes to another room and locks himself in to sleep soundly when our son decides to come and sleeps in our bed, which happens frequently. I'm the one who deals with everything no matter how complicated or silly. I'm so exhausted, yet I have to oversee everything in this house. I wish I could get admitted to a hospital room and sleep quietly for just two days not to worry about anything or anyone.

Umm Hamid said:

I'm the only one looking after him and take him to all his medical appointments and deals with his meltdowns and all other issues. I feed him, shower him, take him to bed and solely look after all of his wellbeing. His father never cares about him when we were together let alone after divorce.

Umm Khalid stated:

My son is so attached to me and won't do anything without me. His father is uptight about everything, so that makes it impossible to involve him, besides I'm the one who does everything here, you know what mothers do for their children, don't you?

The low involvement of fathers was mentioned by all of the mothers with noticeable frustration and anger. This extended to their limited contact with their autistic children which has been a strong objection in all of the mothers. They described how such limited involvement has assisted fathers to not fully appreciate the mothers' challenges in looking after their children with autism and their other children, carrying out family responsibilities and keeping harmony within the house. With despair most mothers noted that even when fathers get involved, involvement is minimal and additional to their involvement, so they do not get a break. For example, one mother said:

I was wrong and stupid to take my son to all of his medical appointments for years by myself without involving his father. He

doesn't fully understand or comprehend what I go through every time I go with my son. I was really sick and was hospitalized for a week, only then my husband started to realize the daily hardship I go through to make everything ok in the house. He took our son to an appointment and finally witnessed the meltdown of our son, with people staring and making harsh comments. It was a wakeup call for me too. Physical and psychological exhaustion was the reason I was admitted into the hospital after collapsing in the house. He needs to get involved to really comprehend the constant stress and the hardship I am under. You know Saudi men never bother with anything and that's hard to cope with an autistic child. He came to me talking about his hard time in managing our son and deep inside I was saying "so now you see and feel what I go through". (Umm Adel)

Another mother explained:

Even if I was a machine, I would have been exploded in a thousand pieces by now. For years I was the only one running everywhere else with my son, you name it hospital, school and everywhere. I know our culture and how Saudi men were raised, but this is different. The situation I'm in is so unbearable, so even a little help is appreciated. (Umm Madawi)

Umm Sultan stated:

From the beginning my husband didn't care or participate in anything. I was literally running alone everywhere with my son. He doesn't even bother to ask about him or go to see him. It feels like it isn't his son, but someone else's. I have no life with him nor respect. Our marriage has ended since that day, we just live in the same house, but have nothing to do with each other.

Having a child with autism is described as affecting the entire family.

Numerous conflicts seemed to arise from the imbalance of the caregiving role which has solely fallen on the mother, on top of the continues stress and fatigue dealing with all of these issues, managing the child and his/her siblings, house chores and everything else. Umm Madawi stated:

It is very hard just to plan to go to (e.g., shopping malls, cafes or restaurants), it is hard to take her as our attention is placed on her, and it is harder to leave her behind. I'm a mother and I am torn between them both. It's hard to go and visit people as not everyone is understands or accepts her weird behaviour. Leaving her behind is killing and taking her is not an easy job. Her sister becomes my other

eye, as she looks after her too. She is the youngest, yet she's bearing such a responsibility, but what can we do? It is very hard on me to see that my youngest is already involved with her sister and as a family many things have changed which we won't able to do as a family.

Umm Zayed said:

I stopped going anywhere with him, he changes my life. It is very hard to manage especially in public, so I just want to stay home. We even have stopped travelling together as a family. My husband and my other children tolerated that for a while, then they left us behind and started to travel. I'm ok with that, but our family structure has been affected and my children are not happy with that.

Umm Tareq explained:

It is hard to go out with all of my children. His brothers are really nice to him, but they don't want him to come when they are going out to meet their friends. He acts awkwardly in front of their friends and that embarrass them. Also, they feel all my attention is going towards him, while they getting nothing, but I can't help it. He needs attention 24/7. They sometimes understand that, but mostly feel upset which is another pressure to live with.

Umm Moudi recalled:

She always fights with her brothers, and they always provoke her. Both don't understand each other. I explained thousands of times to her brothers her issues, but they always fight and run after each other. This is very tiring and stressing. Also, it is hard to leave her and go with them or just go with her alone. Travel plans have been cancelled due to her. Many things have been changed for all our family.

Umm Adel said:

Before we travelled as a normal family, but not anymore. He turned our lives upside down. Once I decided to travel together like before and took him with us. It was a disaster, so I decided that would be our last trip as a family. He completely changed our family life. My children are so upset with me and find it unfair not to travel like before, all these issues add more pressure on me.

In conclusion, the low to almost non-involvement of the fathers was a strong theme which surfaced in all mothers' narratives. Fathers' invisibility from their sons and daughters with ASD in Saudi was

persistent, and its effects throughout the mothers' journey was very evident. Also, notably while mothers tried to explain their endless struggle with their other children, the fathers' invisibility and disengagement in the life of the child with autism in particular and its effect on the mother was the main theme of much of their narratives.

Challenges for the Mothers' Wellbeing:

All the mothers reported that having a child with autism took a toll on their wellbeing. Their journey felt lonely. They explained how hard it was to find someone who really comprehended the full scale of the difficult life they were living. Undesirable support offered by families and friends was discussed by all the mothers, while acknowledging the effort and the good intentions behind it. Umm Sultan said:

My family are kind to me and try to support me in their own way...you know what I mean. They don't really understand what I'm going through and if I try to explain or vent my frustration on, they will stop me and remind me that I'm better than other mothers and I should be grateful and thankful to Allah and stop complaining. I'm not complaining how can I make them understand, I'm very grateful to Allah and I know I can be worse, but I need to talk I need to say something It's not about complaining it is about talking about it.

Umm Madawi stated:

It is really hard to speak about what I'm going through and trying to swallow on a daily basis let alone complain, it is not complaining about why no one wants to understand, it's simply letting go, but it seems hard to achieve. If I go to my mother and start to tell her what is going on she will start to cry hard sympathizing with me, I don't really need this I can't even handle it, I myself need a shoulder to cry on, so instead I have to comfort my mother, which is the last thing I need. I felt suffocated and suicidal, I needed to talk to someone, don't get me wrong though, I feel sorry for my mother, but her support wasn't what I need. Very few friends try to support me, but they don't really understand the depth of our lives as mothers of children with autism.

They would say to me “I’m just exaggerating the situation, things will be ok so stop complaining and live your life”, or if I share with them the slight change we achieve they will look at me like I’m crazy or stupid. It makes you actually feel as a shallow mother, because everyone around you is saying it is ok you’ll be fine. I know I’m not saying I’m dying, I just need to talk and you need to listen as simple as that....but it has proved to be hard.

Most mothers lacked emotional support: to talk and express their frustrations. Talking with a mother of an autistic child or as all mothers put it (*Umm Zayii*), a mother who lives the same circumstances, helped. Most of the mothers did this but with some reservations. Many mothers explained feeling inhibited within these discussions and limiting their talks to autism and its ongoing struggles. Most mothers described how having *Umm Zayii* to speak with about various tawahod issues and concerns were vital for their wellbeing and provided supportive friendships. They found it almost impossible to talk about having a child with autism with mothers of ‘normal’ children, who were perceived as not sympathetic and showing limited comprehension. Umm Tareq explained:

It is really a great comfort talking to a mother like me a mother of a child with autism. It is such a relief that she understands me and understands my frustration like no one else. You know, we both have the same problem, so we are deeply related, I don’t feel embarrassed or ashamed from talking about my situation because she is in the same situation. Besides, seeing a mother living in the same situation makes me feel I’m not alone and we will be alright.

Umm Hamad stated:

No one understands our situation, not even my own family or my friends. They live in their own perfect world. They complain about silly and trivial thing like “my daughter doesn’t know how to brush her teeth etc.”, I can’t take it, you know how it feels and compares with our daily struggles, so my group of six mothers, all of which have a child with autism is what really matters and what we all needed. We understand each other’s situations, go to training together, exchange tips with

each other, and accepts our children without any judgment. They are the real support and strength that I need in my life to keep going. So we talk freely about autism and show care to each other.

Umm Sultan contested that view and stated:

It is really hard to find someone really understands my position and feeling. I tried to befriend mothers like me, but I find it not helpful, actually depressing. They always talk about all the achievements they accomplished with their autistic children and that makes me feel I'm an incompetent mother, I couldn't achieve anything with my son like they did. I felt depressed and sad all of the time. It makes me feel I'm a bad mother who didn't look well after her son, I don't really need this in my life, so the best is to keep away from them and keep tawahod to myself. When I feel down I go shopping which makes me happy for a while, and that is enough for me. Also, when my thoughts start to be too much, I really sleep for a day or so, until things settle in my head. That's my life and I can't change it...

A couple of mothers described how they selected 'the right mothers' for these relationships. Umm Madawi said:

It is very crucial to join mothers who match your social background and equal intellect otherwise it will be a disaster. At the beginning I jointed a couple of mothers who were kind and nice, but their way of thinking was so different from mine, don't get me wrong I'll give you an example. If I talk or complain about my situation and my daughter's issues, they will hush me immediately and say: "be grateful to whatever Allah decided to give you and remember you're better than many other mothers' situations" can you imagine that? If I can't talk and share my frustration and anger with mothers in the same terrible situation, then whom I'm going to talk to? Well I'm grateful to Allah, but seeing my daughter's situation and living it is another matter, so I quit such people. I befriend mothers who I can complain to and be myself with them, otherwise I won't survive the situation.

Umm Ali stated:

I was happy to see mothers like me, you know what I mean, I'm not alone, that was great. We ask each other about tips and training and we learn from each other too. But it is really hard to talk about other family issue with them, so all we talk about is autism. I have to be careful, I can't talk about family issues, our culture and habits. Things have to stay at home.

While all mothers collectively agreed that talking to (*Umm Zayyi*) a mother like them was helpful, they caveated this by saying that talking to (*Allah*) God was their most significant, powerful and inspiring source of support and coping. Umm Adel said:

Allah is the greatest therapist anyone can have, because Allah has the greatest experience of all. When I feel depressed and spiritless I put my (Sijada) prayer's rug and stands between his hand and start to pray and calling upon Allah's aid, protection and inspiration. Allah is the real support and back up, no one not even a mother, a daughter, a son, a brother or a husband will support me and understand me like Allah. Allah understands me and feels my pain like no others, so to me he is my therapist who I confide in with no hesitation or fear. The confidence I have to Allah is great and unmatched. Even Prophet Muhammad had reached out and talked to Allah in hard times. Mothers like me would kindly listen and support, but you will never feel that comfort and trust with anyone. Besides, I can't talk freely about other things like family issues or other concerns just with anyone, you know it is not that easy. How would I know they won't go and talk about it with others.

Umm Johara stated:

Praying and calling upon Allah in the middle of the night is the most consoling for me. I talk and tell Allah everything unreservedly. I can't feel such comfort even with my husband. Talking with mothers like me is great and cheers me up, because they understand me and go through the same difficulties but it is quite different. Talking and asking Allah to direct me to the best ways for training her is such an unmatched relief. I always ask Allah to cure her, because Allah is the one whose capable of such power and kindness. Allah and Allah alone gives health and heals those who are sick. This (Ayah) verse from the Quran is always in my mind "And when I am ill, it is He who cures me" (Surah Ash-Shuaraa-ayah 80)

Umm Salah explained it:

As I mentioned to you that seeking people's help or comfort especially mothers like me is fine and comforting to some extent. You can't just open up with people, it has its limit. I find praying to Allah is the greatest. Praying for me and my son acts like magic. Once he was hospitalized due to high temperature that even the hospital couldn't control, I was desperate, I felt I was losing him as doctors don't know what is going on with him. I put my Sijada and started to pray and calling Allah for guidance and support, while I'm praying and calling

Allah for help his temperature started to drop to everyone's disbelief including me. I was overjoyed. It felt like magic. Allah's mercy and generosity are unmatched. Mothers of autistic children are full of tiredness and sorrow and they have a limit to listen and comfort each other. So, Allah for me all the time any time.

The mothers felt no boundaries with Allah, however, that was not the case even with other mothers like them. While all mothers felt a great degree of comfort and trust with other mothers of autistic individuals, a strong sense of reservation towards what cannot be shared with others was in the forefront for all mothers all the time. Confidentiality of family matters were strong fundamentals shared by all mothers, which controlled and limited their abilities to talk freely or vent their frustrations. In other words, even when talking and discussing autism and its various issues with another mother there were always a limitation to what can and cannot be shared with others. A sense of restriction was always present, even within the limited space created by those mothers where they could supposedly talk freely with one another and share their worries, disappointments, sadness or anger. Mothers kept reminding me that their reservations had stemmed from the fact that family matters stay within. In addition, I was constantly reminded about my own responsibility of protecting the information that they shared with me.

A few mothers warily shared with me that to maintain their wellbeing and to continue on such a (*rehla*) journey they needed the help of some medication. Umm Adel said:

I have been taking medication for a while, basically before having him. No one knows about this not even my husband, children or my own family. You know how our family reacts to such a thing. I'm sharing this with you because I feel you understand the situation and I trust it

is a secret between us. Having a child with autism is a disaster by itself. It has worsened my mood and I have started to feel down most days. You know I live in a state of maximum alert due to his nonstop movements in the house, he is like a storm, if I don't hear him, I know he is up to no good. I don't feel any calmness or comfort until he goes to bed. It is extremely hard to manage even with medication. I still don't accept his tawahod nor adopt to the situation. I really wish to have a portable room outside of the house where I can go just for a bit of escape and to be away from all of it. The problem is even with the drug I don't feel happy nor do I feel I have the energy for my other children. It is not helping me as I expected.

Umm Madawi recalled:

I was having a hard time accepting autism, actually up until now I'm not adapting to it. I started to have suicidal thoughts. For example, when I go out with the driver to run some errands I feel it will be great to hit any car and never go back home, it was a relaxing feeling to get away from the madness I'm living. I was pushed to my limit and no one understand my misery, not even my husband. I didn't find anyone I can talk to. I wouldn't dare to say anything to anyone because if they hear me talking about her situation they think I'm complaining and not accepting Allah's fate, and will immediately advise me to "pray and ask Allah's forgiveness for not accepting what fate Allah's decided for you". I don't really need to hear this and feel lonely. One day I was taking my daughter to her pediatrician to adjust the dosage of her medications. I think she saw how I looked and somehow, I dared to tell her that I have suicidal thoughts that is exactly what I said with no other explanation, so she kindly wrote me a prescription and told me to take it. I bought it and took it that night. It was magic, why didn't I think about it before? I don't really know, besides what would I say to my husband? For him who used to accuse me of being out of my mind calling me (the crazy mother), because I was taking my daughter to different doctors to find answers to her weird behavior. I was doing all this alone with just my suicidal thoughts. It took me three years to convince him that I needed to go and see someone for this, when he agreed I told him I am taking drugs, but didn't tell him the real time I started them. Anyway, I decided to stop them because I really felt ok and normal. Unfortunately, I went downhill it was scary to get back these suicidal thoughts, so I went back to them. (Alhamdulillah) praise be to Allah, currently I don't need it, but I know what to do in case I don't feel ok and get these thoughts back.

Umm Nawaf stated:

I was going crazy as I wasn't allowed to say my son is autistic. All my family especially my mother was against saying this in public. Not just that, my mother was saying that "A good mother never says crazy

things about her children”, can you imagine I was going crazy. I wasn’t saying bad things or hallucinating, it was what the doctor told me. It took years before my mother allowed me to say my son is autistic and she partially accepted that. I was locking myself and him in the house for many years, until sorting things with my family. I was literally going mad. Then I decided to confront my mother because I can’t take the situation anymore. And decided to go to a psychiatrist, I needed someone to talk to about my situation and stop bottling things up, because I’m going to explode. I told him I’m not at the clinic for drugs, I’m actually against taking drugs, I don’t need to be deadened from the situation, I need to talk to release my suffering and share my sorrow. I’m against the drugs world, I also want to be awake and aware, I have other children and many responsibilities, I can’t sleep for the rest of my life. Alhamdulillah, I didn’t need medication I was in the clinic to talk about my suffering and to share it with someone that I don’t know.

Depression and antidepressant medication are highly stigmatized issues within Saudi culture. The few mothers who spoke to me about their experiences of them appeared cautious and watchful. Their voices were low. None of the mothers reported having an experience of being able to talk about their distress and low mood. Those taking medication appeared to be doing so without any planned further consultations. One mother explained how she asked for antidepressants: *“I can’t function anymore, my husband needs things to be done and my other children need me”*; she was prescribed antidepressants without planned follow up. Mothers decided on when to take the medication and when to stop it. The words depressed or depression were not used, alternative phrases used included; *“dismayed, feeling down, didn’t feel like doing anything, was exhausted and wanted to sleep a lot, I couldn’t perform any of my responsibilities towards my husband or children and felt like being alone”*. These depressive-type feelings were perceived as temporary, not serious and caused by (tawahod) autism. They appeared, by avoiding its label, to treat depression as a temporary matter

which would go and would not stay with them as an illness. For example, one mother explained saying:

Alhamdulillah, I didn't need to take the medication for a long time, just for a while to get ok. I don't use it anymore, but if I feel that discomfort again I know what to take to feel better, you know at the beginning it was a shock, like all other mothers then now I'm ok.

Another mother explained:

I just felt down and wanted someone to talk to, importantly someone I don't know. The first thing I did I told the doctor that I don't need drugs. I'm totally against these drugs, I don't need to be drugged, I need to talk to someone I don't know.

The mother continued:

He prescribed some for me, but I didn't buy them, I don't need them I'm normal just want to talk.

A third mother shared that:

All I wanted is to boost my confidence and trust myself more. Also, I needed to accept my situation and to accept my child tawahod and his other problem, so at the beginning just for a little while I used (Dawa Nafsi) psychotherapeutic medication and I'm ok now and I don't need it Alhamdulillah anymore

On the one hand, the mothers did not want to label or talk about their problems. On the other, some intimated that they would like to talk.

Most of the mothers hide the subject from their family, husbands, children and friends. I was reminded constantly not to even mention the subject or speak about it with other mothers. Another dimension of cultural invisibility displayed by many mothers was related to their own psychological wellbeing. For example, hiding their need to go to a psychiatrist and taking medication. Shame and stigma towards mental health exacerbated invisibility and secrecy.

Based on the above, it was not hard to recognize how the wellbeing of these mothers has not been completely addressed or resolved. Such unresolved situations might shed light on why all of these mothers' answers to one of the research questions (how do you describe your child's problem), were in fact describing their own problems rather than their children's problems. For example, Umm Rakan answered the question by addressing her problem:

Well it is a problem no actually a disaster, but I am not going to sit and cry over it. It's ok to cry but I need to do something about it. I have two children with autism which means many problems in the present and many for the future. I had a couple of difficult years, I was broke, all my income had been spent on their private tuition. I didn't have a single penny to spend. My husband is responsible about his parents, so a big chunk of his income goes to them. We literally lived on just eating lentils for a month (e.g., lentil soup, lentil salad...you name it). I can cope with this. The problem is there aren't enough specialized clinics for them and most of them are private, so you need more money to pay for the many services they both need. Governmental hospitals for autism are very limited and you wait for almost a year between appointments, such situations make you stressed and angry, and I don't really need that. Speech therapy services are so expensive and the free ones take 8 to 9 months to schedule the next one, so he will forget whatever he learnt in the previous appointment. Centres for autism are very costly and limited in number. The waiting list stretched from 2 to 3 years. So, without money, my children with autism will hardly survive and I will go crazy.

Umm Salah stated:

I don't know how and what to start with. What has happened is a catastrophe. We both are living a disaster. What is going on is a disaster that literally broke my back into two pieces, yet I need to get up and help him. I'm trying hard to live with it and make things easier for him to live in this life, but my whole life has been severely altered. I left my husband, because he doesn't do anything to help our son. Every doctor we went to, to figure out what was going with our son, ended up either refusing the diagnosis, accusing the doctor of not knowing how to do his job or the doctor's qualification is not accredited. I got tired of this life. For him he just wants me to stop doing anything for our son and closed all doors, something I refused. Divorce was the only solution. This suits me better as I can knock

different doors and try different solutions until I get him out of the tawahod world. (Inshallah) if God wills it will happen, I have huge confidence in Allah that it will happen. The most painful part of tawahod is that I don't really know if he knows I'm his mother or just someone who cares for him? Does he love me? Does he feel safe with me? Who I am to him? I don't know what he likes or dislikes? It is beyond painful, it hurts a lot.

Umm Zayed explained:

It is very hard to describe tawahod. Tawahod is full of unwanted surprises and I suffered differently in each stage. For example, around puberty, it was a disaster. As a mother you are always alert and that's why you are exhausted and burnt out. I don't understand why he doesn't like certain things? I don't find him liking anything. He doesn't choose anything or pick anything, I find this weird. We give him things to play with and choose toys to keep him busy, he wouldn't pick anything by himself. Some of his behaviour is hard to deal with and control. Inside the house I can control him and restrict the unwanted behaviour, but outside the house it is hard to control. I want my son to be socially accepted, it hurts a lot that such a thing isn't achievable. Outside I tried hard to keep him busy, so I can control him. It is so exhausting for me to do so, and it is hard publicly. I want him to act normally outside of the house, so people stop staring at him and us. It hurts how people preserve him. I find it extremely hard to adapt to autism, I don't even know how. It was a very hard at the beginning, now a bit better not that I'm fine with it, but probably I will get used to live with it. Psychologically, I always feel sad and unhappy. I like to stay home all the time and won't go out unless for necessary things. Autism affects me and destroy me and not just my son. It changes me and fills me with sadness until I die.

Mothers' Anxieties for Their Child's Future:

Mothers' fears and anxieties clustered around three main areas: daily challenges of autism and behavioural symptoms; limited resources and the need for more governmental support; and what will happen to them when they die.

The many daily challenges of autism caused all mothers constant worries and exhaustion. Autism's social impairment has remained one of the

most distressing to all of them with huge determination to change it to get the child out of this world, that is the autism world. They also revealed their worries and difficulties in handling other behavioural problems (e.g., sleep problems, hyperactivity, tantrums, toileting/selfcare difficulties, aggression, breaking items, learning difficulties and picky eating...etc). Umm Hamad stated:

It is really hard that he still can't repay the compliment back to people, for example when people bring him a gift he would say "thank you but I don't need it" or "thank you I don't like it", he doesn't understand how to act like normal children and it is embarrassing how do you explain that? I find flapping with the hands another problem, he flaps them a lot when his happy, but normal children find it weird. I am working hard to change all these issues. He really gets scared of clowns, so I started to take him to all activities or parties with clowns' activities, he has to accept it and acclimate himself, otherwise he is missing out and I won't let that happen. More importantly, he has to change and adapt to be like other children. I find forcing him to adapt to the things he doesn't like is working with him. For example, he hates going to the supermarket, I started to take him every day no matter what. He used to cry his heart out, but I won't change because he has to adapt to this. After two weeks he started to go without crying, shouting or throwing tantrums.

Umm Salah said:

It is painful to see him like this he (doesn't understand things around him, doesn't know how to ask for things, doesn't express feeling happy or sad) I feel he is not living his childhood like his sister, it is painful for a mother, but I will do all I can to get him out of this world.

Umm Nawaf stated:

My son can't communicate with anyone even with me or with his father. He can't socially interact. He can't talk like how I talk with you now, and can't initiate any communication. He just uses few words for things he wants, that's it, but no complete sentence. He doesn't understand what I say or when we talk, I want him to communicate so he can live and survive in the real community. The real community is not our house and his school. His world is not the real one. I find him mysterious and an enigmatic boy.

Umm Sarah said:

It is hard that she cannot depend on herself for changing, eating or going to the bathroom. I have always to do it with her. I want her to be independent so she doesn't need anyone, that's my main goal. I want her to be independent so she can look and care for herself without the need for others.

Umm Adel explained:

He doesn't talk not a single word, so I don't know if he can become independent. His nonstop movement, once up from his sleep he roams the house continuously, he doesn't sit and he doesn't get tired. He breaks things, slams doors, and walks on my body when I'm asleep, I don't understand this and it is hard to take him anywhere. A couple of years ago I was with two mothers like me and they were saying that "they wished that their children are physically disabled rather than autistic", I was shocked to hear that and didn't like it. Now I understand what they meant by it. Tawahod is so draining, you cannot relax even in your house, you don't understand why they display this behaviour, and you are alert all the time. It is a hard job and actually impossible to maintain.

Umm Saad recalled:

Last month, all of a sudden, he knocked and hurt my old mother. It was dreadful and outrageous. Alhamdulillah ten thousand times that she didn't get hurt badly. I was so distressed. I didn't go to my mother for a month, just imaging the worse. So, after this incident I started to plan to observe him more and train him not to do such a thing like that. I'm confident I will succeed in that.

Mothers, were also frustrated by the limited resources available and wanted more governmental support for their children. They felt current services were inadequate and that while teachers were doing their best, they need more training and support. Umm Madawi said:

Schools and centres for our children are so limited. Waiting lists take between two to three years and they are so costly. Speech therapy appointment are so expensive because they are private. Waiting time for the free ones offered by governmental hospitals take from seven to ten months. They are overcrowded and not that great. The monthly governmental financial support for children with special needs is so little that wouldn't even cover the cost of three speech therapy sessions, and that is not what she only needs, you know autism. I just

realized that I can't go for early retirement because even with her father's financial support we both still evenly contribute to her expenses as well we need to live decent life with her sister. We are a comfortable middle-class couple and a house owner with very good income, yet staying home won't be an option for me.

Umm Zayed stated:

Autism is an expensive illness, though we have no money issue. My son is around twenty years old, this age group has no services in our country, meaning you keep them at home, alas. Schools and centres services deliver just up to fourteen years old, so we literally pay for everything (medical appointment, speech therapy, private teachers to come to the house to keep training him and entertaining him), I just can't imagine how people with limited financial background can afford it. We are rich Alhamdulillah, yet having a child with autism needs bottomless financial support. In addition, we have very limited professionals, teachers and places for them, meaning money won't help.

Umm Hamid explained:

It is very hard for me to provide him with all the several needed services e.g., medical, therapies and educational, simply because I can't afford them and his father doesn't pay anything for him since we were divorced. I come from a good loving family, but our finances are so limited. My brothers help paying towards my son's expenses as much as they can, so I won't be able to provide him with all the needed services. Some kind people who know us and know of my son illnesses help towards paying some of the expenses, it is very embarrassing and emotionally hard for me, but I really have no other way around this.

Umm Malik said:

I changed my son's school twice, due to the negligence and abuse he was exposed to. It is so painful just the thought that he had to go through such an experience. The real problem is there are very limited good schools and the waiting lists ranging from two to three years, not to mention their expensive cost. The government financial support for these children are pitiful, so we need as a family to balance things out. It is really hard to balance.

Umm Johara stated:

It took me a couple of years to convince my husband to move to the capital city. The town where we used to live is very small and had a very limited medical services and no one knows what is going on with

my child. We all know that all good medical and educational services are based in the capital Riyadh, so we have no choice but to move. Finally, he agreed and we moved, it is a great step forward, but it is so expensive and everything costs so much here.

“What will happen to my child when I die” was the most emotional and physical agony for all of these mothers. All of them unreservedly lost the battle of composing themselves while talking about this exact anguish. Umm Sami stated:

It is emotionally tough. He is now in a residential and training facility in the UAE- United Arab Emirates, so I go to visit him very frequently and every time it is harder than the last. No facilities for his age back home, so it is the only option. I'm in my sixties and his father in his seventies and I don't even want to go there with my thought, but you can't help it. His siblings are loving and caring, but they have plans to marry and life's responsibilities I'm not sure that they have the time, besides his illness is not an easy one. I just can't think what would happen to him, how would he understand that I'm not around anymore. Then I tell myself that Allah creates all of us and he will look after us, Allah never abandons us, but I can't stop thinking when I die who is going to look after him with love and passion. I fear for him because he doesn't talk or complain like us. Then I go back to Allah the creator and believe that Allah won't let him be alone because he knows him and knows how vulnerable he is, so I believe that Allah will certainly send loving people his way. I'm going crazy with this, but tell me what can I do...

Umm Khalid explained:

I'm so worried about him and his future especially when I die. Who will look after him, love and protect him? Is he going to get married and have his own life and have his own children? These are constant thoughts in my mind. Then I settle down remembering that Allah has created all of us including my child with autism and Allah never abandon his people, right? So, I shouldn't worry. Inshallah Allah will protect him and look after him, who else would have such capacity to love and care for his people but Allah.

Umm Nawaf said:

It is so taxing thinking of his future and what he is going to look like when I die and his father as well. I don't want him to be left literally on the street to fend for himself when I die. He is not capable of that. Our community is not passionate about them either. I don't want his

siblings to put him in an institution, I wouldn't bear the thought, just this thought made me die ten thousand times. So, the best solution for all of these worries, I decided with his father to write him a will and asked his two uncles one from my side and the other from his father's side to be witnesses and to be responsible to make this happen in the future when we both die. At least, it gives me a piece of mind and a promise that he won't be thrown on the street.

Umm Sultan stated:

It is hard, I try not to think about it but I can't. What will happen to him? What will he do when I die? Is his father going to look after him? I hate his father and I wish he suffers in his life, because he never helps nor supports me with anything regarding our son. He never bothers to ask about him or even travel to see him in his boarding centre for autism. He left me alone in this. He hasn't seen his son for a couple of years now, there is a huge gap between us and I hate him for not caring for his own son. But still wondering would he care about him when I die? I really doubt this, it is so painful and makes me constantly think of what will happen to him? He is already in another country and not with us. Then I try to leave this problem to Allah and trusting in Allah's plan for both of us and I am sure he will sort it for me as no one else will.

Discussions of the mothers' future worries particularly "*What will happen to my child when I die*", was hard for them and for me. All mothers wholeheartedly shared their realisation of the serious and the immediate need for more support from the government in terms of schools/centres for their children at different ages instead of sending them overseas, therapeutic services, financial aids, recreational centres for autism, family support and more skilful people to work with autism.

5.2 Autism Causality and the Explanatory Frameworks Used by Mothers to Understand the Condition

This section will delve into the different paths taken by mothers during their unfinished journey to discover, understand the child's situation and learn about autism. It explores how mothers have changed and responded to *tawahod* in light of Saudi people's perception of disabilities in general and autism in particular. Also, it will shed light on the different paths which have been taken to understand autism and its impact on the mothers, the family and the wider society. Finally, it will look into the different changes that followed and how it affected these mothers and their lives at large. For example, some mothers talked about longer-lasting changes in their character which included becoming more assertive and empathetic, and more considerate and thoughtful towards life and people. Mothers also created the support they really needed by befriending other mothers of children with autism, while explaining that their relation to Allah remained the ultimate one. In many cases, autism appeared to have given mothers a voice to advocate for their autistic children in an unaccepting culture. To sum up, this section explores how mothers have understand, explained and responded to autism. Furthermore, how their journey was far from over and how it kept changing them along the way.

Causes of Autism: Mothers' Perceptions:

The mothers used the internet to try to understand and learn more about autism as most of them had never heard of it before. This was particularly in response to when a doctor finally diagnosing their child, as the

doctor did not typically provide mothers with information about autism. In addition, for many mothers the word (*tawahod*) autism was completely new and they had never heard it before, regardless of the level of their educational background. Others used the internet prior to getting their husbands' approval to go to a hospital for investigation. This was especially helpful when their husbands denied or challenged their worries.

Umm Hamad said:

I noticed that his performance didn't really comply with his age or with what children at his age are usually capable of. Above all, he doesn't talk and couldn't understand small orders let alone perform them. I opened the internet, you know it is the quickest way to get information and answers, and literally typed (mute child) the word TAWAHOD popped up, so I decided to jump the result and closed my eyes then typed (nonverbal child), in again TAWAHOD appeared on the screen, decided to jump it again and literally closed my eyes before that word, but no matter how I changed and played with different words, TAWAHOD is the only word which kept popping up, so I acknowledged it as a word and looked at, but not reading about it. I didn't want to know what is TAWAHOD, then you know I had to read about TAWAHOD since I learned there isn't any cure for such illness, I felt I had to read and I had to convince myself of that TAWAHOD and then I had to force myself to accept it. I have read tirelessly nonstop about tawahod, maybe too much, then I slowed down then stopped.

Umm Ali said:

Many doctors saw my son, but told me he is ok and nothing is wrong with him. One of the many doctors told me that my son might have tawahod, but he wasn't really sure. Anyway, I have never heard of tawahod before, so I turned to the internet to learn about tawahod. I saw many videos for tawahod with his father and read about it. We both stayed all night up crying after seeing how our son's future life is going to be, we said to each other that "Allah will help us to deal with it and Allah will provide us with the patience needed". We cried on a daily basis and stayed up a couple of nights just crying.

Umm Nawaf stated:

I knew my son was sick due to all the weird things he did. Then when the doctor told me that he has tawahod a word I have never heard before, I couldn't wait to reach home and directly to the internet and

typed tawahod. I started to read about it what it is, what causes it, what the features are of such illness...etc,

The mothers learned and read extensively about autism. I was surprised by the amount of knowledge and expertise they shared with me. However, this was not always reflected in their explanations of autism. A mixture of religious and scientific explanations were recounted by the mothers. Umm Madawi stated:

I think I heard that autism is genetic like other disabilities and illnesses like Fragile X, but autism is still a weird thing they didn't know or figure it out yet. I still really don't know what is autism and its causes, nobody does.

Umm Hamad said:

I don't really know the cause of tawahod, I feel it is something organic and that something is going on in his brain.

Umm Mohammad explained it:

Tawahod has no causes it is just a disturbance in the brain.

Umm Saleh stated that:

If the medical field doesn't really know what's tawahod, how would I know!., maybe the complications during my pregnancy caused tawahod or maybe because I was very distressed during the pregnancy.

Umm Adal said:

There isn't a clear reason for tawahod, it is from Allah, it is my fate by Allah because Allah loves me, by giving me such a child Allah is definitely preventing me from greater harm. Because Allah is all-gentle and ever-kind to his worshippers. In my situation Allah knows my limits, so the benevolent Allah gives me a motawahed child rather than a child with cancer as Allah knows me better, Allah knows I won't be able to endure watching my son with cancer, I would be dead, while with a motawahed child I'm more capable of looking and taking good care of him. Allah knows our limits and abilities and won't give us anything beyond them. Also, I'm sure his tawahod is due to hasad too.

Umm Sami explained:

No one really knows the reason behind tawahod, but after lots of reading and attending many talks and events about autism I feel that the MMR vaccination is the reason for it, generally tawahod (Subhan Allah) Glory be to Allah is a riddle.

To Umm Khalid autism is:

It is (Qada w qadar) one's destiny.

Umm Sarah said:

Tawahod generally is (Iradat Allah) Allah's Will, also I feel part of it is a punishment from Allah to my husband. During my pregnancy he suggested getting an abortion because he didn't like children, but he believes tawahod is caused by Ein.

Umm Zayed stated:

Tawahod disorder is from Allah, with no doubt.

The MMR vaccine was a rich topic of conversation and was commonly discussed by many mothers who believed that MMR could be the cause of their child's autism, as they had noticed that their child's development has hugely changed after receiving the vaccine. Such belief is more common and shared in many different cultures, in contrast to the previously discussed beliefs, which were more culture-specific.

Umm Saad stated that:

I have no doubt that the MMR vaccine is behind his autism. I know a mother who her child was normal and full of life until he took his MMR. It turned off the light in his eyes. he is autistic now. I myself didn't give my last child his vaccination after what happened to Saad and I am advocating to my WhatsApp group of autistic mothers not to do so, I have the evidence before my eyes.

Umm Sultan and Umm Sami echoed Umm Saad's belief regarding the vaccination link to autism, while Umm Johara contested that belief saying that:

I strongly don't believe that the MMR vaccine is what causes autism, simply because my daughter with autism is the twin of a normal sister, I'm sure if there is any medical reason probably it is still unknown.

In addition to the above, mothers cited other different reasons that caused autism. Various medical investigations during pregnancy, birth complications and psychological distress were among these reasons.

Umm Sultan said:

During my pregnancy I was under tremendous psychological pressure. Also, I had some medical issues that needed some medications which it might cause his tawahod.

Umm Khalid said:

I had a complicated delivery with decreased oxygen which might cause his autism, also I delivered him prematurely so he had to spend two months in the incubator, so that could be a reason for autism.

Umm Salah stated that:

Autism doesn't exist in my family (Alhamdulillah) praise to Allah all our children are normal and healthy except my son. I went through tremendous stress throughout my pregnancy and that might be the reason for tawahod.

Umm Saad recalled that:

I had lots of complications throughout my pregnancy, which required lots of CT scans and X rays, which definitely are reasons for autism and I was so emotionally disturbed by all of these issues and my psychological wellbeing was really bad and I felt so down. Feeling such sadness through pregnancy definitely caused autism.

A couple of mothers cited that antidepressant medications could be a reason too. Other mothers also mentioned that a deficiency of vitamins, mainly vitamin B during pregnancy was a suspected cause for their children's autism. Umm Tareq said:

I blamed myself for not taking vitamin B during my pregnancy, so I'm worried that deficiency caused his autism.

Umm Adal stated that:

I sometimes blame myself for taking antidepressant medication during pregnancy, but other mothers didn't take them yet they have a child with autism, I really don't know, no one does.

Dental filling was cited as a reason behind autism and mentioned by three mothers. They felt that other mothers should be warned about this.

Umm Faisal explained by saying that:

I really wish that you will focus on this in your research as I feel it wasn't given any attention. During my pregnancy I had a couple of new dental fillings which I'm convinced played a great part in causing autism. It is important to research this matter.

Only three mothers from my participants doubtfully suggested there might be some familial (*aila*) genetic cause of autism, even when I asked about this directly. Umm Rakan said with a very low tone which I struggled to hear:

In our Aylah we have many members with different issues. My father was a "Home alone" kind of person with very fast movements and grumpy moods, I feel he was an ADHD kind of person. In the past I was a very annoying and daring person and whatever I did, it didn't go well with the strictness of my father so I think I have ADHD too. My sister had two normal children, but the third one I think has a problem, they didn't get a diagnosis, but I don't think she is a normal child.

I asked her to clarify that "so do you think there is a family connection to autism?" She replied:

I don't really know, I'm not sure but I feel we have a problem within the family, again I strongly believe in hasad and I believe that my husband and me are (Mahsoden) we are envied from others.

Umm Sultan explained it:

I really don't know, I don't know. Maybe "Warathah" heredity from my family side?! Maybe!! Maybe who knows! because we used to have a child who was diagnosed with autism in our family, but he isn't autistic any more. He went to the US and has been treated and studied there. He's a normal person now, so I am not sure about Warathah.

Umm Faisal said:

I feel one of my eldest brothers was autistic, but sixty years ago nobody knew what tawahod was!! That's why we should ask this question and investigate it? You should cover this in your research more than other subjects.

I carefully shared with Umm Faisal that there are a couple of papers which have already talked about (*Warathah*) autism's heredity as I know how sensitive it is to share the families' illnesses in Saudi as it is common for the community to portray to that their family are healthy and have no issues. Nevertheless, she did not comment and went on to tell me that it is important to look at this between all the Saudi families and try to understand what is going on and that was that, she then moved on to talk about a different matter.

In short, while most of the mothers accessed the internet to search and learn about autism, even the few mothers who had heard of the word *tawahod* before knew little about what it meant to be autistic in everyday life. Overall, most of the mothers, regardless of their educational background, and even when highly educated or working in the medical field, were unaware of autism. They knew little of its existence and had no previous knowledge of it or any familiarity with the characteristics of

autism. Mothers collectively offered various explanations for autism including religious, cultural, or limited scientific explanations. However when it came to genetic explanations, they gently pushed away and reconstructed the family link differently (e.g., *Hasad*) envy. Generally, most of the mothers did not consider that genetics might contribute to their child's autism or show awareness that such links exist, they simply offered alternative explanations.

It was revealed throughout all mothers' conversations that very limited information about autism was available to them especially from reliable and trusted sources (e.g., hospitals, doctors or organisations), thus they heavily relied on the internet to gain knowledge and understanding of autism which sometimes might offer a misleading or false information. Another explanation for such inclination (lack of knowledge or acknowledgment of genetic contribution to autism) could be culturally explained.

In the public eye, Saudi families want to be viewed as perfect, their members healthy and with no obvious physical ailments. Having a child with special needs (e.g., autism) would be publicly challenging and would negatively affect their families' reputation and pride within their communities as it contradicts that family ideal genetic status. Therefore, it is common among most Saudi families, as we have seen, to keep the affected child or individual hidden from the public. The attempt to detach themselves and their family members from the real etiological causes of the problem and displacing the causes of autism on to other nonfamilial

reasons could also be viewed as a defence strategy to keep and maintain their family status. Accordingly, other reasons and explanations for their child's disability could be culturally more acceptable and less stigmatising to both the family and the child.

Giving Meaning to Autism:

This theme explored how Saudi mothers of children with autism made sense and gave meaning to their experiences. All the mothers I interviewed were practicing Muslims, and all described drawing upon their faith throughout their (*rehla*) journey to make sense of *tawahod* and try to construct meaning around their child's disability.

All the mothers in this study have utilized different techniques to cope and adjust with their child's autism such as; spirituality, the support of (*Umm Zayii*) a mother like me and from their family. However, their individual beliefs behind having a child with autism is very important in helping those mothers to put *tawahod* into perspective and construct a worldview in which *tawahod* and its predicaments made sense and were explained. Since religion in Saudi plays a central role in interpreting and understanding everything in people's lives, constructing religious based explanation for autism was deeply reflected in all mothers' rationalisations. The question "*why do I have such a child*" or "*why me*" was asked endlessly by all these mothers throughout the interviews. Mothers offered many explanations and meanings to their own question, almost all religious in nature. Umm Salah explained:

Tawahod is a test from the gracious Allah, but why I'm the one who have been chosen amongst my eight siblings, why me? I always ask myself this question. I feel Allah chose me because I'm the best for this test, I'm the strongest and I'm the one who will patiently tolerate this problem. I see it as a trust from Allah, he trusted me to look after him. It is (Hiba) gift from Allah that distinguished me from all the others. I was given a chance by Allah to show my hidden potentials in dealing with tawahod.

Umm Adel stated:

Tawahod is my own destiny by Allah, it is Allah's (Minha) gift. By giving me an autistic child, He is preventing me and my family from the million other vilest things that could happen to us like cancer. Allah shows his mercy to me by giving me a child with tawahod which I can bear and tolerate than a child with cancer which I won't be able to endure and look after. Allah knows us better than we know ourselves. Allah knows that I'm a great mother with unmatched passions and love for my children, so he trusted me to look like even with having tawahod. My son with tawahod is my indisputable (Path) to Jannah.

Umm Sara said:

Tawahod is Allah's will for her, it is her destiny, if Allah wants her to lead and live normal life he would easily could grand that. Who else has such power?.

Umm Saad explained:

Tawahod is Allah's Minha and gift for us. Children with tawahod are the (Barakah) is the attachment of the divine goodness to a human, so s/he is a flow of blessings and grace in our lives and households, in our lives in our houses. They are our guaranteed keys to (Jannah) paradise. We are really blessed, but unfortunately many people receive them as Allah's punishment for a wrongdoing. This is wrong way of thinking. I know some mothers who think this way and people have told them that their children is disabled due to something they, the parents have done, I can't believe it.

As discussed above, all mothers have attributed and attached their child's *tawahod* to Allah's will, destiny and/or *minha* (a gift from God), all of which have evidently empowered and aided them in their ongoing coping journey. In fact, they felt blessed to be chosen specifically by Allah for such a task, a task that comes with great rewards, rewards like no other, it is

Allah's reward (e.g., the guaranteed keys and *tariq* path to *jannah* paradise). Most of them cited and referenced from the Quran and Hadith their promised reward. They also have personally believed that Allah took into consideration several factors and personal qualities before choosing them to care and look after such a child. For example, their loving nature, caring capability, patience, perseverance and endurance were factors cited by all of the mothers before *Allah* made his decision to give them such a child.

Such a religious narrative to account for the personal hardship was central in all mothers' interpretations for autism and for them as being exceptional mothers. Additionally, their take on being *Allah's* chosen mother for such a child in fact helped them in elevating their social statuses among their families as well as publicly. By attaching religious explanations and meaning to the negative cultural and social notions of disability, those mothers in fact were trying to help ascribe a positive status for their children, who were usually perceived as different in their communities.

While all of the mothers cited that their perseverance and strength to adapt and overcome the constant challenges stemmed from and were empowered by the feeling that Allah is always by their side in such a (*Ibtala*) trial or test. A few mothers, however, voiced aloud their questioning, concern and rejection to accept the merit of such an Islamic teaching. They clarified it by stating that such an explanation that having an autistic child is a trial or test by Allah to his beloved people, could or should not be related, understood or accepted by those mothers in such a situation. Umm Nawaf said:

When I was considering tawahod as ibtila, I wasn't happy and suffered a lot, I was about to lose it. Why ibtila even from Allah, it is hard to accept it, what for, why suffering? then I decided to see it as (Makramh) Allah's special gift, any gift from Allah is welcome and much appreciated. Who wouldn't want a gift from Allah? My son is Allah's makramh and inshallah my tariq to jannah. This what has helped me and boosted my confidence and provided my with strength to keep going.

Umm Madawi strongly stated that:

I refused to take tawahod as ibtila or punishment for our sins. What have we done? what sins did we commit to deserve this? Why her? Why she receives the punishment on our behaves? assuming that we committed a sin? This is unacceptable. What sins have I done to be punished by my daughter? I didn't drink alcohol or do drugs like people in the West? Yet, not all of them have children with autism, right? So what sin did I commit to deserve tawahod? All my life I was religious and devout person to Allah, so what had I done that bad to give birth to a child with tawahod? Her father is so caring, helping people and volunteering for a good cause, where is the sin in that? It is beyond painful, after all these years of studying our Islamic teachings in our schools and university, I realized the need to do my own research to understand the real meaning of Islam, because it can't be this. Then they tell you it might be a trail or test as stated in the (Hadith) record of words by the Prophet Muhammad, the Prophet said "Allah does test those people most whom he loves most". Why? It is so painful? You know what? I don't want Allah's love, what love is that? What she is guilty of to pay for? Explain to me? Nobody does or even know. This is can't be Allah's love to me or to anyone. I reached this low point, can you believe that? To say that I don't want Allah's love is huge and devastating, but accepting tawahod as trail or punishment for sins is a NO NO. No one in their right mind believe that Allah who creates all of us would this!! I can't accept that, right?. Oh one more thing that really drove me crazy for a long time, is like I'm living a rosy life without any worries and I need such a test to rethink my life. I was also told that I should look at my daughter's tawahod as a test by Allah to endure, in turn my status will be risen, which stated in the Hadith "Calamity befalls a Muslim as either a punishment for sins or a test to raise his/him status", I just can't and won't understand nor accept that. How a tribulation is good for the believer in the sense that reward is stored up for the Hereafter, it couldn't be accepted and endured? I have a long journey ahead of me, I'm aware of that. I need to research and understand why Allah created us and what roles do we really have in such a tribulation. I realized that coping is a long long process and needs a lot of work to understand things first then I can cope, things still bitter and hard on me.

Umm Hamad explained:

I rejected the idea that tawahod is ibtila long time ago. It is NOT ibtila, it is just a test from Allah and there is no reason for that. I/we haven't done anything to merit the ibtila. What really keeps me going in such a hard reality, is that as a Muslim I'm guaranteed the (Ajr) reward by Allah. This guaranteed ajr by Allah is what really matter in my situation and my real drive to endure tawahod. The feeling that I'm certainly rewarded is what elevate such a tragedy. And I undoubtedly believe that what is distinguished us from the Western mothers. Westerners' mothers don't have this sense of ajr, they don't understand such reward. It is not possible that they have such a reward. As we all know, no ajr without Islam or (Imaan) the belief. This spiritual reward increases from the performance of good deeds and piety, so everything I do to my son and I endure I am rewarded for by Allah, even my patience is rewarded too.

While many mothers acknowledged *tawahod* as Allah's test or trial for them, a couple of mothers refused and debated the idea that *tawahod* is considered an *ibtila* trial. They rejected the idea of sin or trial befallen upon their children because of something sinful they have committed. Such a revelation usually invokes deep fear among Muslims, feeling that they may have upset or done wrong to Allah. Instead they acknowledged it as Allah loves them and therefore sends a trial upon them by sending an autistic child to look after and care for. Hence, distinguishing themselves as Muslim mothers who were guaranteed the spiritual merit *Ajr* reward by Allah for their patience and endurance unlike non-Muslim mothers. This feeling aided them in that Allah had a plan for them, in which autism made sense in the context of that plan and that they would be rewarded by Allah.

Not all the mothers accepted these religious positions unquestioningly. Umm Tareq commented that:

it is hard still hard to see him like this and when I feel this way, so down I go to my mother and moan. She would say that I have been chosen by Allah because Allah entrusted me with tawahod, I feel encouraged by hearing such words, but you know it doesn't last for long.

Another mother commented that:

seeing your own beloved child like this is not what Allah meant by rewarding, if Allah loves me, why would he make my child autistic? I can't understand it.

On the one hand all of the mothers relied on Allah's support and their spirituality to have helped them to endure and cope with *tawahod*, on the other they are still hoping and working to cure the child from *tawahod*. For example, Umm Salah said:

I'm sure Allah is giving me the chance to show him my diligence and determination with my child and will get him out of tawahod, integrate him in the community and treat him from tawahod, just give me the time and you'll see

Another mother echoed the same:

I learned that tawahod world is so fragile and weak and with Allah's well and strength I'll take him out of that

They felt there is another meaning for life and religion that they have not yet understood and yet to be discovered. Notably, the questions "*why I have such a child?*" or "*why me?*" kept recurring continuously with all mothers, regardless of the explanations and the evidence which used passionately and emphatically by both groups of mothers.

In conclusion, all mothers employed a religious explanation to construct meaning for autism and for their ongoing hardship. While it is evident that the religiosity of the mothers was a central mechanism for coping with autism and its constant stress and burden, some mothers warily demonstrated ongoing internal conflicts about the offered religious interpretation (e.g., *ibtila*) by Islamic teachings for such a hardship. A few mothers reservedly shared their conflicts with a few words of clarification

offered to my additional questions for elaboration. Only one mother carefully shared her new approach of looking deeply at the merit of such an explanation after asking me to turn off the recording machine. She said “*this is unacceptable, it will need another long journey by itself to find out answers and I just begun*” as she was not convinced with the offered religious explanation to such a hardship. It also showed that mothers’ religiosity and the bond they established through various practices with *Allah* in their constant struggles of understanding or accepting autism is very unique and has a different personal experience to each one of them. Undoubtedly, autism has altered some mothers’ perceptions of the deeper meaning of their lives as well as the religious interpretation behind their journey.

Cultural and Societal Beliefs in Response to Autism Onset and Diagnosis:

Mothers explained with much sadness and distress how for a long time they believed that they were the one who caused autism in their children. This often related to members of their family, even their husbands, blaming them for infecting/causing their child’s autism. Umm Saleh explained it:

My husband told me that “because I left my son with the maid when he was 9 months old and I went back to work he becomes ‘motawahed’ autistic, he was too little to be left with a maid who can’t speak Arabic and that affected him and got him into the world of autism”. I believed him for a while, but when I thought of how many children stayed with the maids while their mothers go back to work without developing autism I stopped believing such a thing.

Umm Adel said:

My mother-in-law said that due to leaving Adel with the maid alone and travelling he became motawahed. After a year or so when she mentioned the same blame to me I answered her back saying "well all your daughters leave their children with the maid, still they are normal and didn't have tawahod". We have a lot to deal with I don't need these accusations anymore. I believed her for a while then looking around me many people leave their children with the maids to travel, yet they are normal children. People here don't really realise what mothers of autistic children go through, they don't even feel our pain. We are alone in this.

Umm Madawi was explaining this matter with such frustration saying:

My daughter was a rigid and difficult child from the very beginning, actually since she was born, so she used to be glued in front of the TV and watch it nonstop. If I dare to turn it off she will cry and scream hysterically and nonstop and turn the house to an unbearable place. She has a TV obsession, actually the only thing she loves and care about, so I let her watch TV as much as she wants to, why would I want to interrupt her and get her start that cycle of crying and screaming, so I thought to myself that maybe watching TV made her (motawaheda) autistic and the long and intense hours deepen and increased her tawahod.

Many mothers recounted that their mothers-in-law believed that their grandchild's tawahod is caused by (*Ein*) or (*Hasad*) envy or evil eye. In several cases, fathers and mothers, also attributed autism to the *Ein* effect. A common first reaction to symptoms was for grandmothers or parents to take the child to a (*Sheikh*) religious healer for help and cure. Healers' visits varied in their intensity, from one to four days a week. While some parents followed the sheikh's advice very strictly, some decided to discontinue these visits and instead read themselves some of the Quran's verses to their children and/or play the Quran to the child on a recording player on a daily basis before bed time. Many mothers explained and listed numbers of adversities experienced by the child and/or the mother in each visit to the *sheikh* (e.g., the journey to the sheikh place being a tiresome and long for the child; the atmosphere in the sheikh's place was too frightening for the

child; the large number of people waiting around which added pressure on the child and the mother. Further to this, some children feared the voice of the sheikh during the reciting of the Quran or during holding the child for the recitation by the sheikh). All these factors contributed to withdrawing from such visit. Mothers, in general, held the belief that (*Ein*) and (*Hasad*) could be a cause for autism or a contributor to it; it is a prevalent cultural belief that receiving the evil eye causes harm or misfortune to the (*Mahsood*) envied person. Even the very few mothers who did not believe that the evil eye caused autism to their children, recounted that their husbands believed this. They also admitted that while they generally believe in the evil eye concept and acknowledged its effects on people, they did not attribute their child's behaviours to such a belief. They still considered reading the Quran, which was perceived as a fundamental treatment, if not the greatest treatment and remedy for all illnesses and disease within the Muslims' world. Almost all of them used the same text from the Quran as a strong proof of the Quranic power of healing. Al-Isra is the 17th *surah* (Chapter of the Quran) with 111 *ayah* (verses). Al-Isra takes its name from the first verse, which tells the event of the Isra (transportation of the Prophet to the farthest Mosque).

-81- And we send down in the Quran healing and a mercy for the believers -82-

In addition, the belief that both the child and/or his mother was possessed by the *jinn* was also mentioned and explored by some parents.

Umm Tareq said:

My mother-in-law strongly convinced that her grandchild's troubles is caused by Ein, so she didn't leave any sheikh she heard of without taking my son to him to read verses of the Quran on him. Also, she took him to many (moaleeja shabeeya) traditional/indigenous women healers who practise folk treatment. I really don't mind she's doing that. Personally, I wasn't convinced to take him to healers because I believe autism is the illness of the modern times, yet I strongly believe in the many benefits he gets when I play Quran and rub his body with some special oil before he goes to sleep. it really calm him down and relax him, so I absolutely believe in the Quran's effects on him, but never convinced he is possessed with Jinn....no way.

Umm Saad said:

I do believe strongly in Ein in general and I believe that my son's autism is caused by Ein. He was so cute and beautiful, so everyone around sees and comments on his beauty. Also, I was the only one among my sisters-in-law to have two boys and they all have their children but not boys. Every time I visit my husband's family his father-in-law treats me differently, with recognisable admiration and pride as the one who gave birth to boys not girls. It is very hard for me, my father-in-law is an old man who holds many traditional beliefs and one of them is that boys are the best and better than girls and I can't change his mind. As a result, my sisters-in-law are jealous and feel the pressure on them and that in turn affected my son with the (Ein) the evil eye and affected me too, as we told by the sheikh. Thus, we went for three months in a row to the sheikh, who read verses of the Quran on him and on me and gave us some oils and plants pastes to apply to his body. In addition, up until this day I play on daily basis for him the (Ruqyah Shariah) exorcism/incantation in Islam when he goes to sleep. Also, I am strongly convinced in the power of the Quran, as some certain verses are so powerful, in which they enhance his brain cells and boost the dead ones.

Umm Hamad explained her views on 'Hasad' saying:

I do believe in hasad and its effect on people's lives and health, but I don't see this as a sensible reason for my son's autism. Also, I believe in the power of the Quran on my son and on his autism. It is different the Quran is Allah's holy words to us for our good, protection and health, so using and reading Quran is great protector with other benefits for all of us.

Umm Johara said:

Though my husband strongly held the believe that our daughter's autism is the result of Ein which is due to her beauty and charm, regardless whether it is Ein or not, I personally doubt Ein in her case,

nevertheless I strongly and without any doubts I am convinced that reading the Quran and using Alruqyah Alshariah is the real treatment and healing for anything.

Umm Sarah explained it:

My husband is convinced that Ein is the reason behind our daughter's autism, therefore he took her to a well-known Sheikh without me as I wasn't really believing in that. The Sheikh told my husband that the Ein is received by the mother first then passed to the child, so I needed to go and see him to get the help myself then to my daughter to be cured. Also, he told my husband that the evidence is so obvious in me as the Ein I received is preventing me from going to the sheikh to seek his help. I went with them and he read verses of the Quran on me and on my child and followed all his advices including washing my child with special leaves' paste, but nothing had changed. I didn't care because nothing has changed. Her father took her to another Sheikh who told him that it is a black magic received by our child...I never went with him as I really wasn't convinced with any of that, besides we haven't seen any change.

Umm Nawaf stated:

At the very beginning I did believe it was Ein he is really a handsome boy, besides many relatives and friends mentioned the Ein too and advised us to go to a Sheikh which we did. Also, we believed for a while that he was possessed with jinn and went to many Sheikhs for help. Now both me and his father frequently read Quran for him and play the Ruqyah Shariah for his protection. We really feel that the Quran really relaxes and calmes him. In addition, we constantly give him (Moyat Zamzam) Zamzam holy water to drink. I guess at the beginning we did like all parents of children with autism did, we followed all the possible paths to get him healed.

Umm Malik stated:

I believe it is Ein as we just moved to our new house and simultaneously got pregnant with our second child by Allah's will without any medical help which was unlike my first one. You know unfortunately people do envy you for the slightest thing in life and wish to have it for themselves instead. Also, I believe it is qada w qadar (Allah's Will, fate) too. My son got the mix of both.

Umm Rakan stated:

I strongly believe in Hasad, with his father we both created a comfortable life for ourselves. Also, among my siblings I have five children and really adore looking after them, whereas my older sister

got just three and they always say that that I love having lots of kids, so hasad is real and I believe in it.

From the above, it can be established that most of the mothers at the beginning believed that they were the reason behind their children's autism and explained how they were made to feel guilty for a long time by their family members and their husbands based on unfounded causations and their scares knowledge of autism. Also, most of the parents of the child with autism held the belief that autism could be caused or resulted by *Ein or Hasad* (evil eye). In the Arab culture, receiving the evil eye would cause harm or misfortune. Such belief system stems from the culture and the society where these mothers usually live.

In short, some mothers offered a culturally based explanation for having a child with autism by relating autism to supernatural causes. Those mothers showed how their cultural belief systems and values have influenced their perception of having a child with autism. Such explanations could provide a culturally meaningful way of understanding autism and in turn cope with it. Both religion and culture were demonstrated to be central to all the alternative explanations offered by the mothers regardless of their educational background.

Transitional Experiences of Autism Diagnosis:

This section describes how the mother's understanding and explanatory models changed over time in a fluid and dynamic process. All mothers acknowledged that at first they avoided admitting to themselves what were they seeing, and decided to ignore the unusual behaviours for a

while in the hope things would turn out to be normal. One mother stated that:

It was really strange behaviour, but I was saying to myself it is just me exaggerating the situation, and my husband doesn't even care and thinks I'm a crazy person not our child.

Umm Salah said:

He had many medical issues and we used to go to the hospital a lot and spent days and weeks there, so with my personal suspicions towards his developmental delay, it seemed we both (me and his father) were consciously happy to have been forgotten about those worries and put them to rest even for a short time.

Umm Sultan stated that:

When he completed his first year he notably stopped cooing and babbling, there was complete silence not a single sound I could hear from him anymore. I took him to the doctor to check on him and he told me "he is fine a bit of delay like other children", so I was so happy because I wanted to kill all these nagging thoughts about these issues. When he was two years old I took him to another doctor and she told me "he is normal and has no tawahod just speech delay" of course, I was over the moon, very happy because I don't even want to believe anything was wrong with him let alone autism. The doctor said what I wanted to hear. My denial was so deep, I am still in denial.

There was a loud long sigh with comical laughter mixed with tears and it was very noticeable that her mind went somewhere else. Silence filled the grandiose guest room where we were talking. She stayed like this for a good seven minutes then came back with a sad smile trying to mitigate the situation saying "*I'm sorry, but what were we talking about?*". I told her that if she liked to stop the interview that I am happy to do so, and suggested to her that we could rearrange to continue the interview another day. She replied "*I don't mind stopping for a while and talk about general stuff while having Saudi coffee then I'll see how I feel*". I agreed to her suggestion. During the next two hours, most of the talking, which she initiated was about tawahod

and the unstable and sad lives of the mothers of children with autism.

Although, it was intended to provide respite, our break was difficult and full of emotional stories recalled by her.

When the strange and the unexplainable behaviours of the child did not go away, all of the mothers and in this stage all of the fathers initially sought a cultural explanation. Mostly this explanation was by (*Ein* and *Hasad*) envy or evil eye, and less commonly Jinn possession. Therefore, the (*Sheikh*) religious healer visiting to read verses of the Quran and to perform (*ruqyah shariah*) was the first step to addressing the strange behaviours with evident encouragement from fathers. Umm Johara said:

It was a long and excruciating (rehla) journey for us. We used to go to the sheikh three time a week and it took us the total of two hours' drive every time. We didn't know what' was wrong with her, but her father believed strongly in Ein. I also consider ruqyah a cure for anything and through Quran Allah's words to us help and cure will be achieved. We also travelled to a tiny village in the mountain to the northern of Saudi, where a famous healer woman was located and well known to cure anything by her ruqyah. It was a long trip and a very dangerous road drive up in the mountain on an unpaved route, but we were desperate. In a hindsight, I don't know how I agreed to go to that dirty place and to put my daughter between the hands of a woman who before our eyes treated a child with putting her thumb inside his mouth and then blood was everywhere. Later we heard that a child died due to such a practice, but she still claim that she can cure people from anything including autism.

Several mothers were told by family members and friends that the child is probably suffers from *Ein* or *Hasad*, so mothers have themselves to read the Quran for their children and not just verses of the Quran but the whole Surah (the term for Chapters of the Quran) and in particular, (*Al-Baqarah*) the cow. *Al-Baqarah* is the second and longest chapter (*Surah*) of the Quran. *Surat al-Baqarah* is believed to protect the person who recites it

and its house against the evil eye. It also bring immense (*Barakah*) blessing, peace and dispel Satan from the house and protect all its members. Where the cause of autism is perceived as the evil eye, reciting Surat al-Baqarah from the Quran is believed to help in the treatment and prevention of such conditions (*Ein, Hasad*) and preventing Satan from staying in the house. The Prophet is reported to have said to his followers that “*do not make your house like graves, for the Shaytaan runs away from a house in which al-Baqarah surah is recited*”, the Hadith narrated by Abu Hurairah. In Islam, it is believed that reading verses or some chapter of the Quran over a sick person can cure both mental and physical illness as well as diseases. For example, a verse *ayah* in the chapter *surah* Al-Isra was used by most of the mothers to proof the power of the Quran.

-81- And we send down in the Quran healing and a mercy for the believers -82-

Similarly, another *ayah* was used by most of the mothers:

-80- And when I am ill, it is He who cures me -81- And who will cause me to die, and then will bring me to life again -82- (Surat Ash-shuarr {the poets}, ayah 80-81)

Most of the mothers at the beginning especially before any official diagnosis followed heavily on the cultural path of tackling any issues through religious means. However, with time and after getting the diagnosis most mothers favoured to play the Quran *ruqyah shariah* for the child on daily basis or sometimes read it over the child themselves. Saudi society is very

religious, therefore spiritual therapy is religious in nature and most Saudi people have used this spiritual therapy to treat different illnesses and diseases, be it physical, mental or psychological. Mothers of children with autism are no exception.

Umm Nawaf recalled:

I was told I have to read Surat al-Baqarah for him every day, which we did at the beginning. You know as parents we did what other parents with autistic children would do. It was really long and we both me and his father get so exhausted. I couldn't do it any longer. The whole situation was hard and new for us. I then decided to just recite the ruqyah shariah as I strongly believe its power.

Umm Madawi explained it:

I was told to read Surat al-Baqarah for her every night if I want to sort out her unexplained problems. Which I did. It was hard and strenuous to do. It takes around fifty minutes to complete the reading. Locking her with me in a room all that time it was a battle by itself. It exhausted both of us. After a couple of months, I stopped because I was drained and burnt out. Besides, she didn't heal from the weird behaviours or changed. I decided then to keep the ruqyah shariah and played it every night.

However, when the aforementioned cultural religious belief (*Ein*, *Hasad*) evil eye and its intervention did not solve the child's behavioural problems, mothers sought a medical explanation. Mothers at this stage were not even allowed by their husbands to talk about their concerns to their close family let alone get their permission to seek a medical explanation. Such a period was therefore marked by unexpressed worries that forced the mothers to live silently and alone in their shattered world. When they voiced their worries and intuitions to their husbands they mostly were not listened to and were asked to hide the child's oddities from all their families. Paternal disengagement from the child and from what was going on was painfully

cited and reflected upon by all of the mothers. It took from two to five years for the mothers to convince the fathers to permit to seek medical investigations. Only three mothers sought help earlier who in their family did not require such permission. These mothers explained that since they are solely responsible for all their children's needs and the one in charge, the father's permission was not priority for them. Also, one mother Umm Adal mentioned that the father is not involved in any matter regarding his child, so she is the one to take the decision.

His behaviour was so weird since he was very little, and since I am the one who really was in charge of our children then I decided to take him to be checked and didn't really need to check with his father, as he has never been engaged with his children's needs. I'm the one responsible about them, so I decide.

Umm Ali recalled:

My husband thinks our son is ok and all these issues will disappear at some point, and since I am going to deal with most of the steps of this journey without asking or bothering him with anything, he wouldn't oppose me.

This stage was marked by mixed emotional responses from all of the mothers and from the very few fathers who were engaged in this phase. The first step taken by all mothers and by the few fathers to help their child was collectively religious in nature. It reveals how dominant religion and cultural based beliefs were within Saudi parents and both were the first to be employed to address issues within the family.

The mothers' quests for medical understanding was marked by relief/devastation and hope/disappointment. There were often many different visits to different medical professionals, which resulted in a number of diagnoses hoping to get something other than *tawahod*. Most of the mothers

shyly shared that while they wanted an explanation about what is going on with the child, *tawahod* was not expected or anticipated. Hence, the diagnosis was perceived as relief/devastation and hope/disappointment were explained by Umm Hamad who stated:

First time, I went to a doctor he told me "he is ok just speech delay which will go later" I was so happy, though all my internet research said otherwise. Decided to live with this happiness. Well his behaviours were consistent with the internet description of autism, I needed a whole year to confront another diagnosis and to get rid of all my negative feelings toward autism, you know how it feels. This time I wanted his father to be with me. He was outside of the country, we talked and I booked for another diagnosis and we went together. This time the doctor said "he has tawahod"...I hated it why say tawahod, if he said autism would be much better. My life was crushed before me, still I'm not convinced. It was an intense period mixed with manic reading, as I was opening many pages about autism in the internet and three books on my lap. I stayed in that stage for a while until I was hit harshly by the fact that there was "no CURE no CURE for autism", I had to force myself to accept autism. I went to another specialist and she said it directly to my face that "he is autistic". I knew I had to work at that. I want be like other mothers where they go for new diagnosis every six months, but I think I'll do it every year or so to see where he is in autism.

Loud sigh. All of a sudden, she went silent then looked away forced a smile and looked at me and said "*how about having some coffee*", then continued "*you know life goes on whether we like it or not.*" Umm Sultan echoed the same pattern:

I went to four doctors through different ages of my child. The first two said "it is a speech delay which will go when he grows" I was ecstatic and happy to kill all my suspicious. Then another well-known neurologist, who requested hospital admission for a couple of days to run all the tests and CT scans required. We did, and he got the diagnosis of autism, I decided not to accept it...I admit I have a deep denial about it. Up until now I still didn't stomach it. Anyway, not until he was seen by the fourth doctor, reluctantly I had to accept his autism. I said (Amantu Billah) I affirm my faith in Allah and shall go ahead with that. His father didn't care and didn't do anything about it he doesn't even care if he is dead or still alive....

Umm Malik stated:

After a long battle with his father I insisted on taking him for a diagnosis. The first doctor said “he has an ear infection and gave us treatment”. The thing was he doesn’t talk until late and speaks weirdly, you know that and flaps his hands. Then when I checked the internet it said tawahod, which was the first time to hear such a word and I grew uneasy reading more about it. I insisted again to take him to another doctor, who told us “he has autism spectrum, and told me not to worry at all”. I was so pleased I thought that the autism spectrum was completely different from autism I have read about. Then we went to a third doctor, after CT scan and various IQ tests he told us and confirmed my fear that he has autism spectrum and explained to us what it is. His father didn’t trust the diagnosis and didn’t like the doctor’s method. It was a shock and still it is after all this.

Umm Johara said:

We went to a couple of consultants before moving to Riyadh and they told us “she is normal and nothing is wrong with her”. Well her twin acts differently, so when I put her weird behaviours in the internet I got tawahod, (ya Allah) Gosh how I hate this word so much. So, after lots of negotiations with her father he agreed on moving to the capital to seek better doctors and get better services, you know how it’s like to live in a little town!. Anyway, we took her to a specialist in Riyadh, do you know I was in such denial it was an unacceptable thing for me. I even refused pronouncing the word. When I went for a diagnosis in Riyadh and the doctor confirmed her autism, I told her father that she has got that thing I call it thing. To never say the word was hard and I struggled for a couple of years to accept saying the word. For now, I use autism as a definition but she is much better than other autistic children. She is more of normal child, with the training and the school, in a couple of years I feel she would be more like normal children

From the above it can be seen that religious and culturally oriented beliefs were the first to be sought in the quest to find answers by all of the families regardless of their educational background or social status. Both mothers and fathers revealed a constant denial of the child’s strange behaviours while each had dealt with it differently. Most mothers were requested by fathers to keep their worries about the child’s condition to themselves and banned them from discussing their worries even with their

own families. Such behaviour, as discussed in the previous chapter, demonstrated how fathers themselves have contributed to the invisible culture of children with autism, which have already been maintained by others such as schools and centres for autism, the wider community and the families. Additionally, it sheds light on the fathers' concealed shame for having a disabled child. Delaying and preventing medical help by fathers assisted in keeping the child free from any diagnostic label, and in turn, maintained the family reputation too.

In their quest for medical explanations, it can be seen that all the mothers and a few involved fathers were trying to make sense of their children's strange behaviours, but their responses to this were far from resolved. Some mothers received the diagnosis reluctantly with reservations, while others did not accept it and were still struggling with it. Following diagnosis, clearly a mixed emotional response was characterised for most mothers, hence the usage of two contradictory descriptions of relief/devastation and hope/disappointment. In conclusion, most of those mothers' transitional experiences were still ongoing and far from settled.

Changes in Mothers' Character:

The sense of social exclusion towards their children with autism was highlighted by all of the mothers. Various explanations (rejection by their immediate family members due to the child's unusual behaviours, ridiculing the child's behaviour by the public and sometimes by their family, mothers' own sadness towards their child's bizarre behaviours which were witnessed

and mocked by others) were offered by the mothers as necessitating such exclusion. Umm Tareq stated:

My whole social life has changed. I can't go anywhere like before, and I can't take him with me. He needs lots of attention, besides he repeats words and sentences and that behaviour is not socially accepted and puts me in unpleasant situations, so there is lots of pressure on me.

Umm Ali said:

It is really hard taking him with me even to my family. My brothers didn't accept him and complained about his behaviour. People are harsh too and always tell me that "I didn't bring him up to be a good boy", it hurts a lot. With all this criticism and the continuous unkind words, staying at home is the best for us, though hard, and I feel rejected by the community.

Umm Judi recalled:

I stopped visiting friends and families. It is very hard, I feel sad when I see all the other children play together and she was left alone. She is not included in anything. And I find the way people look at her is not bearable nor acceptable, so staying home is the safest way, besides it kills me when I see my nephews and nieces coming back to their mothers, which she never did.

Umm Nawaf explained:

My whole life has dramatically changed, tawahod has separated me from my social life and cut me off life altogether. I locked myself in from the whole world and still I am. I have a zero social life and I don't go to any social gatherings anymore.

Mothers found it hard to socially include their children with autism, as well as being unable to work. They felt that society rejected their children. They mostly felt cut off from their previous social life and lonely. Some felt their religious belief was strengthened and found religious rituals brought tranquillity and comfort. They were perceived as powerful tools in their relentless *rehla* (journey). Umm Tareq said:

When I pray in the middle of the night calling for Allah's help and support for my son, Allah responds immediately and I witness it on him next day.

Another mother stated that:

When I read and recite certain verses of the Quran in the middle of the night over my sons, I see the effect of calmness on him immediately and on me as a mother. Allah's words work in a magical way.

Undoubtedly, autism effected and changed all of these mothers' live.

All of them passionately described the ways in which these life changes, how the changes affected their personalities and their perception of life. Mothers also explained how their experience of their child's autism has affected their own personal growth and altered it completely. Many changes have enlightened and renewed their already embedded Islamic teachings.

Umm Rakan explained:

I used to love songs and sing along with them. I also used to love wearing nice dresses and going to parties and dancing with my friends, all that have changed and I stopped listening to songs and going to parties. Tawahod connected me deeply to Allah, that in turn gives me the tranquilly and calmness I desperately need. The more I'm present and deeply connected to Allah, the more I feel Sakinah (support and assurance sent by Allah into the hearts of Muslims), and I was in no doubt that Allah has chosen the best for me, that is my two children with autism. Having a disabled child in my life has guaranteed a smoother life for my family where Allah's presence is felt and his blessing always direct us. With Allah, I'm stronger and have more patience in life.

Umm Madawi recalled:

I really used to love music and going to parties to dance with my friends. But all that has changed. I stopped listening to songs, or going to social events and changed my appearance to a very humble one I became more religious and adhering strictly to Islamic precepts. Everything about me has changed. Life was taken from me and I have changed too with autism. I started to listen to Quran on a daily basis and play it in my bedroom so it helps me to sleep as well as I play the Quran everywhere in the house. I prayed a lot and endlessly begging Allah to take away what was wrong with her. I did all that at the very

beginning hoping the tawahod would go away and disappear. To me at that time, that is what I should do, if I want my problem to be solved, but it didn't! And let me tell you, it didn't feel good as I went through a rough time. Now I'm more balanced and things have gone back to where they should be. It was a period I went through like many other mothers of children with autism.

Umm Zayed said:

Tawahod made me closer to Allah in a different and deeper way. As Muslims, and in time of Mihna (test or ordeal), in which tawahod for me, my connection to Allah has deepened and strengthened immensely and intensely. I started to perform Munajaat (whispered prayers in a deeper manner on a daily basis), communicating and begging Allah's guidance, patience and asking him what I really want. Also, I make lots of Sadaqah (giving of alms or charity), on his behalf and mine, so good things will come his way and ours as a family.

Umm Hammad stated:

I have changed a lot, I am a better person with tawahod. It makes me more aware that a different hidden community existed, like the disabled community, I had never thought of them or knew they existed, I was so selfish. I wasn't aware that people do have lots of troubles in their lives, even if I don't see it. Before when I saw a child crying and kicking in a mall, I used to harshly judge his mother as being careless and who doesn't know how to bring a child up. I wasn't aware that people especially with special needs children need lots of help and support, but won't say anything about it and keep it to themselves, like me now. Also, the smallest thing would make me happy and cheers me up.

Umm Zayed explained:

With tawahod I learned to be modest and feel for others. I started to have sympathy for people as I used to be very judgmental and hard to please. I was an extremely independent person and I absolutely achieved everything by myself, to my pride, which I am proud of. All of sudden all that has changed and I started to need help from other people like teachers, staff and tolerated their harsh criticism about my son (e.g., he's aggressive, he bites me today, he hits his friend....etc). I became a mother of a motawahed son, so I heard lots of complaints about his behaviour and I won't say a word, if anything I show my gratitude and deep appreciation even to their criticism.

Umm Madawi said:

The rosy life I used to know isn't there anymore. Normal children with a normal life aren't mine, that nice family portrait..you know what I mean. Before I wanted to fit-in and follow what others do and do like them, not anymore. My understanding of life has changed tremendously. I'm more aware of myself and my family needs and what makes us happy. I don't follow people and I don't care if I don't fit in anymore. So, with tawahod, I live moment by moment. I was a perfectionist in all of life's aspects that has changed too, I learnt a different way of living that works the best for us as a family and me as a mother. I gave up many things in life to get the balance I needed and was grateful for the smallest gesture.

Tawahod provided a different lens to see people's different situations and consider their predicaments. The mothers' sense of other people's concealed needs was furthered and the little things in life were described as giving more pleasure.

Advocacy and Activism:

A couple of mothers I interviewed were involved in different activities to advocate for their children and help other mothers who could not afford services. One mother commented: They realized that they needed to put up a fight for their children as they cannot talk for themselves, so they became their children's voices. Also, the general lack of awareness towards autism in Saudi that coupled with limited services available only to the age of 13-14 years old with limited access, led to many mothers getting involved in different activities to advocate for their children and help other mothers who cannot afford the services and access it.

We can't change people, but we can change ourselves and our families to be more comprehending and accepting of autism, by that I hope we are setting a positive example.

Another mother told me that:

I started to accompany a mother who herself has an autistic child and is involved with many poor and disadvantaged mothers of children with autism, to see how we can help financially, psychologically and educationally. Life is so tough on them and with limited money on their hands and with zero support from their husbands and families their situation is so dreadful, if you come with me you wouldn't believe how they live with their children.

Two mothers ran a WhatsApp group that engaged and advocated for other mothers. They divided them into two groups one for mothers who had received the diagnosis some time ago and the other for the “new mothers”.

One of these mother told me:

I have been there before, you know I felt so lonely and frightened not to know what is going on with my son and when I learned about tawahod for the first time, I didn't know before what it meant. It was hell, so I really want to pay back and help these mothers to focus on training their children as quickly as possible and not to waste time like I did. Also, to provide them with psychological support, which is essential for mothers' well-being, otherwise they won't survive such a thing. Hearing other mothers' stories give them the inspiration they need to keep going and to know that someone out there is always ready to offer help and support.

Other mothers took the role of advocating for their children with autism by giving talks and using their own experience to share publicly in universities and charities. One mother said:

I feel so comfortable to say it out loud that I'm a mother of an autistic child and share with the university students my obstacles and difficulties, so they can understand what we mothers are going through and try themselves to make a change in the future, or at least not to judge people before knowing what is going on. By listening to my story I'm hoping they go and share it with others and spread the word hoping for change even if a slight one, where our children become acknowledged in our society.

Some other mothers had got involved and volunteered to work with a charity for autism, in which they advocate for the difficulties encountered by

families of autistic children and the support they need. In addition, they help register mothers with children with autism, who have not been registered in the government system and oversee their progression to get all the government financial support allocated to children with autism. One mother told me:

Since we don't really know how many children with autism we have in Saudi, you know there isn't any official report, people keep talking about numbers but no report supported that, it is a great opportunity to register them, and from there we hope we can help them to access the government subsidies in which will advance our agenda with the government too.

Another mother volunteered:

Inshallah will help put our children on the map and pay off for other mothers. I like it here I meet mothers like me and talk with mothers who are going through the same (rehla) journey, they really understand my difficult life like no other, even my family and friends don't get it, so it is a great feeling to help new mothers, be useful and reduce their hardship by our advice which we have accumulated by being there before them.

One mother said:

Even if takes a hundred years to do it I won't give up until I die. Children with autism are like other children, different yes, but never less important and they have the right to be acknowledged by everyone including the government.

Through their various forms of activism and advocacy, these mothers seemed to share one collective goal which is their desire for their child, themselves and their family to be accepted, included and receive an equal amount of respect and love that other families and children enjoy. Also, they want to make sure that the government is fulfilling its promises towards their children as well as all other children with disabilities.

5.3 Various internalised and externalised stigmas associated with autism and the relationship of the condition to disability and disablement

This chapter explores how mothers have recognised and responded to *tawahod*. Such responses cannot be disconnected from Saudi societal reactions for disabilities in general and autism in particular. As discussed earlier, publicly Saudi families prefer to be viewed in perfect shape, in that their members are healthy with no obvious physical ailments and in great physical condition. Having a child with special needs (e.g., autism) would be publicly challenging and would negatively affect their families' reputation and pride within their societies as it contradicts that family ideal genetic status. Accordingly, it may have a direct social consequences such as decreasing the prospects for relationships and marriages opportunities.

Stigma: Negotiation, Language and Communication:

All mothers expressed their various concerns and frustrations regarding the social stigma associated with disabilities in Saudi culture. They explained and reflected on how generally people in Saudi perceived an individual with any kind of disability, but gave more in-depth and thorough insight about children with autism and their continuous painful experience and struggles as mothers. Mothers also shed light on the fact that autistic children look physically normal, yet their abnormal and challenging behaviours do not serve their case well publicly. In addition, they discussed

their concerns about the negative reactions from some relatives or from the public and communities. Umm Saad stated:

You know our culture, most people think any individual with special needs is (Majnun) crazy or mad, all of them unfortunately are mentally retarded and crazy in the eyes of most Saudi people. It is so painful to see how they have been portrayed them as less worthy, our Islamic teaching is so the opposite from this cruel common understanding, but here we are.

Umm Ali talked about her painful experience with tears streaming down her face and with noticeable struggle in composure saying:

He used to struggle to spot me among many of women gathering in a large guest room, so he would go around trying to find me by staring at their faces and sometimes he would mistakenly sit on another woman's lap, but would get up and continue to find me. You know what they say, while he is sitting on my lap? "He is majnun" "your son is brainless" "he has no brain he has pistachio" and they laugh hard at him. Children too mocked him and laughed at him. They even call me "Umm almajnun" mother of the mad, it is so painful, but Allah will help me and support me to be strong for him.

Umm Zayed said:

You hear all sorts of different painful things from all people regardless of their educational background or their relation to you. For example, once a mother told me "(Mashallah) God has willed that your son can swim!!, I didn't expect that from children with tiny brain", it hurts so badly, it feels like a knife cutting into your heart and you can't do much about it, just bottle it up and hope for a better tomorrow. Once a relative of mine, her child undressed my son with the help of other children, they were laughing and mocking him that he was just standing and doing nothing, when I found out I was so upset it HURTS I still feel the pain, so I told them it is wrong to do that and went to her mother telling her about the incident, so that she could explain how wrong it is to do such a thing, instead she laughed saying "your son is a retarded and disabled, so he does these stupid things himself". It hurts and all you can do is to cry for a whole day and night, then what?! It'll happen again, so I really have stopped socializing and going out, I stay home, which is much better and less painful.

Umm Hamad said:

Actually, even children look down on him not just adults. You know autistic children, they flap their hands when they feel excited which he

does a lot, children usually laugh or stare at him and mostly leave him behind and don't play with him.

Umm Khalid recalled:

One day he came back from school with his (thobe) gownlike garment worn by Saudi men-dishevelled and torn, I was upset and I asked him what's going on?? He didn't say a thing or complain, you know autistic children! I went with him as usual to help him change and to my horror and shock I found bad words writing all over his tummy...I was boiling and screaming from rage and anger to the point his father was running upstairs towards us thinking a stranger broke into our house, he was shocked and suddenly was so quiet, and actually looked defeated. Hard as it is and harsh we have to educate the whole country.

Umm Sami said:

He loves the little public garden in our neighbourhood and loves to play in the children swing, he would swing for hours and it is always empty, you know, people here don't really come to such a thing nor their children, but he was like their TV they were crowded in the little park which they never cared about to just watch him and laugh.

Mothers described with such obvious pain and sorrow how the public in general belittled and mocked autistic individuals. In turn, such stigma was a constant source for their endless worries and fears for their children as well as their relentless stress.

A common reaction described was feeling sorry for the mother and the child as he/she is not "normal". Mothers found this way of showing compassion unacceptable. A sorry look or a stare was often viewed as hurtful and negative. One mother said "*I don't want people to feel sorry for me or him, just leave us alone*". Another one explained "*spare me this kind of care if you are looking down to her, I am going through a lot and I don't need your hurtful stares*". All mothers rebutted such compassion where people felt sorry for them and showed this to the mothers. They instead

emphasised the importance of acting normal towards the child and his/her mother and spared them the negative unwanted support.

Mothers voiced their struggle and sadness especially in public places as their children with autism exhibited different challenging behaviours, which drew extra attention, undesirable reactions and hurtful comments from others. Also, they expressed their struggle with their own immediate family members towards the child's challenging behaviour in public where they felt ashamed of the child.

Umm Hamad explained:

When people see him they always start to tell me that they are making (Dua) calling out for Allah and communicating with a deity (God)-for both of us and ask Allah to heal him and give me the strength for helping him. To me while I appreciate their intentions, it really hurts that they feel so sorry for us, you see it in their eyes. Every time they would tell you that they feel for this hard life I'm having!!! Why they assume that, can't they just talk normally without bringing up this issue every time we meet!! Also, once they hear he has tawahod they would say oh (Miskeen)-poor guy in a pitiful way. As a mother I don't really need such sympathy because it hurts A LOT.

Umm Johara stated:

The problem is that even my own family want to literally guide her everywhere and control her all the time, I know it is out of love and care but she doesn't really need that, it hurts because you know deep inside that they see her less capable than normal children so in a way they start to control her hold her hand all the time. The other day I was in a shopping mall with my brother and she was walking three steps ahead of us, he jumped and held her hand, she was so annoyed, I told him "she's ok and safe just leave her hand" he replied "well she is hyperactive and moves a lot, people are looking at us" it's so hard on me, I know this overprotection is out of love yet he is embarrassed because of the way people were looking at her.

Umm Nawaf said:

We went to the hospital for an appointment, you know autistic children are unpredictable, he got upset and had a meltdown in the women's

waiting area, you can imagine the scenario, right?! He decided to lie down on the ground kicking and shouting, it is beyond my control and the situation was far from any explanation, yet all the women in the room even men came to the women's restricted area and crowded around him/us, and everyone volunteered something "read some verses of the Quran" "hug him" "help him to sit"...etc. Because he was in such a mood, he felt threatened and annoyed by all those people circling around us, so he started to hit them, of course I heard lots of colourful language "you didn't know how to discipline the boy" then this guy started to yell at him, it was miserable and I was so angry and outraged.

Umm Saad stated:

I don't like this negativity (e.g., why feel sorry for him) I don't accept this kind of love. I know they try to show their sympathy but it hurts. Autism, so what. Treat him naturally, he is different but not less. Even within my own family I tell them that he is unique in having autism. Also, when I introduce him to people I say here is my hero who is autistic. I want to show positivity, why do we have to be ashamed by autism? believe me the autism world is so fragile and boring, why the fuss? People feel sorry for us because in their views such a child has no future and some people think these children are just a burden.

Several mothers commented that having a child with special needs is still considered a taboo in Saudi culture where families usually feel embarrassed from them and as a result keep them in the house and away from people. Umm Tareq said:

While my own family is very supportive, caring and always welcoming him with open heart, I feel as well as my family uneasy to have him around when having a social gathering. He does look like a normal child you know how autistic children look, actually very handsome, so people can't tell. The problem starts when he starts to talk with the guests, you know he talks but so weirdly and repeat things around, and that when people start to notice that something is wrong with him, so I decide if we are having guests, I leave him at home. It is better than answering people questions. He embarrasses his father when he hosts his friends and colleagues, especially by repeating nonsense sentences in front of them, so he asked me to keep him inside with me and not to let him go to his father. It is hard on us, but our community is critical and reactionary regards disabilities in general and still not ready.

Umm Madawi explained the situation saying:

Our situation is so complicated. She has many behavioural issues and difficult personality. She is obsessed with the iPad and the iPhone, so if she sees them she is going to get them no matter what. The scene would look so ugly, because I have to literally fight with her to take it and give it back to people, not to mention that she goes and takes any bag if she sees one of these handsets in it. It is extremely embarrassing, so how and what would I explain to people. I feel I want to die in the spot, so I don't really take her everywhere, we just go to my family and some of my very close friends who understand our situation, even that I find it hard to stomach seeing her behaving in this way. The very few times we decided to go out with her to a restaurant as a family, people didn't stop staring at us due to her weird behaviour, and some volunteered to come and asked questions about what is going on with her!!, so I was extremely stressed and felt exposed. Do you know I can't even say hi or welcomed our new neighbour, simply because the father approached my husband and introduced himself and invited him for a coffee, then he asked him "we hear weird voices coming out is it from your house?" my husband dismissed the question, he couldn't answer him and I wouldn't either, so I wouldn't go and welcome them.

Umm Ali recalled:

When I go to visit my mother, my brothers directly say it to my face "we are leaving because your son behaviour is weird, annoying and unbearable when you leave we will come back" even though, there are no guests around just us. They are ashamed from us. My mother was angry at them, so they have changed a bit. They stop saying all the hurting stuff, but won't stay that much when I go. I started to go in the time when they are not around. It is hard and painful enough in the outside world and when it is from you family it is devastating.

Umm Adel stated:

Actually, his paternal grandmother forgot about him long time ago. She wouldn't even bother to ask if he still alive! Six months would pass without asking to see him, so painful and it hurts a big deal when even his own flesh and blood are rejecting him. My mother and my family side are much kinder and more acceptable of him. If there are guests or social gathering I don't take him with me, he is hyperactive and keep walking around nonstop and cause lots of trouble, so it is better to leave him home otherwise I will shadow him and won't social with people. You know what I mean. Also, I don't like to explain his situation to everyone, people are already good at disapproving. I have two close friends where I take him with me when I go, they are kind,

welcoming and don't get upset when he accidentally breaks things, and when they come to visit me they don't mind him being around.

Umm Sarah said:

It is very hard people don't accept them in public areas and they made it clear, heart breaking for me.

Umm Malik stated:

Tawahod is very hard and extremely distressing illness and taking him everywhere is not easy. I took him with my in our small family gathering, but the other big extended family gathering I don't, simply because not all off my cousins know about his illness. Besides, he just learned a couple of questions which he'll go around and askes each person these questions and will demand their answers and attentions, it will be embarrassing and uncomfortable because he doesn't know when to stop. We didn't even tell my brother-in-law about his autism, so when we go to visit them I leave him with my sister. My husband doesn't want his family to know, you know he doesn't want to see them keeping their children away from him. People sometimes get uncomfortable and don't really understand him.

Umm Nawaf expressed her painful situation by saying:

My mother in particular condemned and scolded me for many years for telling them that my son has autism, she refused to accept that and disallowed me from saying it to anyone else. She used to say to me "this is all rubbish, you are hallucinating, don't voice this nonsense to the outside". It was tremendous pressure and pain on me, for couple of years I couldn't say a word and was in ongoing battle with my mother and my family. Is hard to live such shame and fear and worry all the time that people might know and my mother will be so angry. Is like I need more stress in my carefree life. It was awful feeling and living. Only when I decided to stand up to her and admitted that I have an autistic child without shame, I started to feel better. Having an autistic child is extremely hard and make life complicated, so I don't need more anxiousness.

All mothers collectively revealed their complicated family arrangements with regard to their child's presence. The arrangement was far from clear and usually applied according to the social arrangement of each family. Overall, while mothers discussed the support they received from their family, they also reservedly disclosed the limitations to such

support. For example, when the family hosted a social event with external family members and friends, it showed that the child would not be welcomed. In turn, the child would be kept at home. Various reasons were given by mothers to justify their family arrangement such as they wanted to protect the child from outsiders' negative views and/or they did not want other family members knowing about the child's disability. In addition, a few mothers discussed how some of the children's grandmothers have strongly refused to accept autism as a diagnosis and in turn forbidden the mother from revealing it to anybody. Other grandmothers had stopped wanting to see their disabled grandchild. As one mother put it *"his granny doesn't bother to ask about him, doesn't even care if his dead, to her he's already dead"*.

More importantly, mothers themselves concealed their own feelings of shame related to the child's challenging and unusual behaviours especially in public places. They themselves usually kept the child at home most of the time to keep his/her disability hidden or secret. Feeling a sense of shame made most of the mothers reluctant to take their children with autism out in public. Similarly, most of the fathers hid the child and his/her autism from their own family and banned the mothers from speaking of the child's disability to their side of the family. They tended not to take the child with them when they visited their immediate family and always used different excuses for not bringing the child along.

All mothers collectively refrained from elaborating about their family's stand towards disability when I asked them questions to clarify. They instead became very dismissive and generally defend their families. For example,

they would say “*our family just want to protect us*” or “*you know how our society think of disability which put our family in a hard position*”. Commonly all mothers would prefer to talk about others and strangers (e.g., Saudi society and Saudi culture) to shift the conversation from their own families. It was obvious that all mothers showed discomfort and reluctance to discuss either their family or their own embarrassment or humiliation from autism or disability in general. Instead they focused on Saudi social stigma of autism.

In addition, mothers were concerned that people’s negative perceptions of autism would affected their other children including their child with autism, therefore they felt the need to hide autism from friends and neighbours. Instead they offered another label (e.g., ADHD). They said autism scared people from befriending them as well as preventing their children from socialising with their autistic child. Umm Hamad explained it:

I didn’t tell his friends and their mothers that he has autism. People once they heard this word “tawahod”, they tend to change and treat him differently or feel uncomfortable towards his friendship with their children. It is hard, but this is the best way for now.

Umm Tareq told me:

I placed him in a mainstream school and told them he has ADHD. People treat him like retarded child when I say autism. Besides, when I put him at the very beginning in a school for autism, he didn’t improve and picked many bad habits from them. Now he is much better and learn so much. He is not like typical autistic children. Even my husband doesn’t want me to say tawahod, we say he has ADHD and has speech delay. Similarly, people’s views towards him change positively and treat him like a normal child. So, don’t be surprised If I we meet somewhere and I don’t say he is autistic, I know you would say anything just want to make sure and gives you a heads up on that.

Umm Zayed said:

Do you know a friend that I know very well told me not to mention to people that my son is autistic, I was surprised and when I asked her

why not? she said “will if people know he is autistic they won’t come in the future and ask for his sister’s hands in marriage, you know our culture, they are uncomfortable and not ready for such a thing”

In Saudi society, individuals with any type of disabilities are still viewed as “majnoon, mentally retarded, miskeen”, and mothers recounted the stress of living with these attitudes. Umm Tareq said:

I really wished he is physically disabled, because people show nicer attitude towards them as immobilised people are considered to have a brain but tawahod have no brain and no sympathy from people.

From the above, it can be concluded that all mothers felt more comfortable and at ease explaining and talking about the effect of social stigma and the societal reactions towards their disabled children and them as mothers, but strongly resisted any chance to talk about their own causes of humiliation or their sense of shame. Also, they showed discomfort and gently refused to talk about their own family embarrassment or their sense of shame toward the child’s disability. Instead, mothers generously offered to discuss the role of social stigma and Saudi society’s reactions to disability. Some mothers cautiously talked about their husbands’ constant embarrassment due to their child’s behaviour, especially in public places, and how they always tried hard not to be involved with the child publicly. Mothers explained their various struggles with their husbands who were not just in denial but refused to be supportive and felt overwhelmed with shame from their child’s disability. As a result, mothers felt alone in this journey, and were left by themselves to assume the responsibility for caring for their children’s needs and dealing with autism privately and publicly.

Owing to the fact that Saudi family life is exceptionally a private matter, they were constantly hesitant to offer me details about the challenges they were facing with their own families. While all mothers generously let me into their own private lives and struggles, the cultural fact of being Saudi meant that the mothers were reluctant to openly voice certain experiences and concerns, even when it comes to research. Honour and social family pride have both shaped and constructed the way the mothers reflected out loud with me, and consequently, certain issues would always be concealed from the public eye, in this case the researcher.

Chapter 6: Discussion

This chapter will review the findings of the study in relation to the relevant literature and the conceptual frameworks discussed in chapters one, two and four. I will discuss the implications of the study for the field of special education, autism practitioners, educators, psychologists and parents in Saudi Arabia and globally. I will also reflect on the strengths and limitations of this study and finally, provide recommendations for future research.

Interpretation of the Findings

This ethnographic study sought to explore and understand the experiences and religious coping of Saudi mothers' caring for and bringing up a child with autism in KSA. I explored how these mothers recognized and understood autism, what their cultural beliefs and understanding of autism were and how they adapted and coped in raising their children. I also explored their overall concerns, worries and needs regarding their children with autism.

The results of combining both participant observation fieldnotes and the in-depth qualitative interviews enabled me to identify four major themes with sub-themes. *Mothers' Unfinished journey*, was the overarching global theme which transcended three major temporal organizing themes. (*Autism invisibility within the wider society and the difficulties of getting and dealing with the diagnosis; Autism causality and the explanatory frameworks used by*

mothers to understand the condition; Various internalised and externalised stigmas associated with autism and the relation of the condition to disability and disablement).

There are several points of contact, and contradiction, between the current findings and previous research. The four main areas for further discussion are (1) the impact of religious beliefs on understanding, coping and raising a child with autism, (2) autism's impact on the mother and the wider family, (3) stigma, and (4) the impact of inadequate and limited services. I will discuss each of these in turn, before considering the limitations and implications of the study.

The Impact of Religious beliefs

The study illustrated the ubiquitous and deep influence of Islam on the mothers of children with autism. All Saudi Arabian citizens are Muslims and the cultural environment is conservative with a strict interpretation of Islamic Law applied to all aspects of life. All of the mothers in this research frequently referenced and overtly demonstrated how Islamic values and religious beliefs affected how they responded to the stress engendered by raising such a child and how they tried through their faith to create meaning to understand and cope with the ongoing challenges of autism and its impact on their lives.

It was not just religion that helped those mothers to understand and cope with autism, culture also played a significant role. Together religion and culture were intertwined. Throughout the mothers' deep and vivid narratives,

the interconnectedness between religion and culture was so refined and most of the time hard to untangle.

The influence of religious beliefs concerning disability is globally widespread. In several studies on families of children with disabilities from different religious backgrounds, it was seen that religious beliefs played an important and significant role in informing understanding when it comes to the interpretation, explanation, responses, and acceptance of the disability (Skinner, Correa, Skinner & Baily, 2001; Shaked, 2005; Gabel, 2004). Further, it has been found that many parents of children with autism and children with developmental disabilities regarded their children as a blessing, a special gift from God and having a high spiritual status (Skinner et al., 2001; Shaked, 2005).

It is not only the parents' religiosity that played a vital role in their understanding or accepting of a disability, but the cultural background of the family has been deemed as significant as religion. Culture plays a role in shaping the way people think, see, and understand the world around them. According to Gurung (2006), it comprises "a dynamic yet stable set of goals, beliefs, and attitudes shared by a group of people" (p.127). Therefore it is not one or the other, it is a combination of both. Thus, the spiritual and cultural background of a family, together with the wider views of a society, influences the beliefs parents hold towards the cause of human disabilities.

As a member of a certain community, the lives of individuals with ASD are generally determined by the culture in which they are immersed. This is

similar to the finding of Ravindran & Myers (2012) who discussed that individuals with disabilities are part of different families and communities which reside in all parts of the world, therefore their lives are largely shaped by their culture. They also explained that all families and societies do what they believed is the best for individuals with disabilities which also corresponded with their cultural values and beliefs. Consequently, the beliefs held by members of a community regarding the potential and treatment of individual with autism would differ from one culture to another and might change over time (Ravindran & Myers, 2012).

Since cultures vary in their interpretation of disability, the ways in which people perceive, experience, and manage health, disability, and illness are clearly cultural concepts (Rogers-Adkinson, Ochoa, & Delgado, 2003), and thus it is important to gain a better understanding of autism not only in the Western cultural context but also across different cultures (Daley, 2004). For instance, in the West, the diagnosis of autism and its recognised causes are primarily attributed to a scientific medical model. Although, as discussed in Chapter One, other models have been considered more recently e.g., the social model of disability and the neurodiversity movement. Corresponding with the models established in Western societies, different treatments are available in the West including behavioural, cognitive, sensory, pharmaceutical, vitamins and diet therapy.

In other cultures, however, the causes of autism might be regarded as “Karma, Allah’s will, or the will of God”, and might be treated with non-scientific remedies such as acupuncture and/or herbal medicine (Ravindran

& Myers, 2012, p.311). In Riyadh, Saudi Arabia where this research has been carried out, the results of the thematic analysis established that in regards to the causes of autism most mothers held a combination of cultural (e.g., envy or evil eye) and religious (e.g., autism from Allah or Allah's will) views rather than scientific/medical ones and believed strongly that the child would grow out of it.

This finding corresponds with the findings by Almana, Alghamdi & Al-Ayadhi (2017), who stated that while a good number of Saudis had heard of autism and had some knowledge of it, most of the Saudi community paid less attention to the organic causes of autism and believed it to be a psychiatric process and the children would outgrow it with proper intervention. More importantly, by attaching a cultural meaning to autism e.g., evil eye and subsequently believing its cure lies with religious scriptures, mothers of children with autism in Saudi not only reflected their religious and cultural values in all aspects of life, but showed the extent to which both culture and religion could influence their willingness to seek help from specialists.

In terms of the various models existing in the West to understand and explain autism, the results of the thematic analysis in this study revealed that the medical model (which considers disabilities as deficit), was the only available model pursued by mothers to diagnose and understand their children's "unusual condition". Neither neurodiversity nor the social model of autism were mentioned or discussed by any of the mothers who participated in the study and the mothers I met in different events. Further, these

alternative models were not mentioned by the different professionals or teachers in the field of autism in Saudi. This shows how different cultures with different beliefs provide people with different lenses to understand and perceive disability.

Following the diagnosis of a disability, religious parents may draw upon their faith and belief to aid them with making sense of and constructing meanings around disability (Jegatheesan, Miller & Fowler, 2010). In this study, the mothers showed the significant role played by religious beliefs in interpreting and explaining disability. Most of the mothers offered similar religious explanations and meanings with regards to how they perceived autism and what might cause it. For example, most of them explicitly referenced the cause of autism as the Will of Allah, my fate by Allah or Allah's predestination and Will. They considered autism/*tawahod* as Allah's hiba/minha/gift. This is similar to previous research findings, even amongst different religious backgrounds (Tarakeshwar & Pargament, 2001; Mirza, Tareen, Davidson & Rahman 2009; Jegatheesan et al., 2010; Ilias, Liaw, Cornish, Park & Golden, 2017). Based on existing literature by Hussein (2012) he explained that regardless of the different explanations offered by people for having children with intellectual disability, the situation does not usually result in a passive or negative response to the child. He explained that when people perceived disabled children as either "gifts from God" or "tests from God", those parents were led to develop an intrinsic motivation to care for the child. In other words, such beliefs work as a religious incentive to care for their autistic child and continue on their ongoing journey.

Most of the mothers in this study evidently exhibited their religious beliefs in interpretations of disability. For example, the concept of *Ajr*, reward by Allah, was cited by participants with respect to having, caring for and looking after such children and these endeavours were believed to never go unrewarded by Allah. Many mothers felt that having and caring for a child with autism is their guaranteed *Tariq* path to *Jannah* Heaven as well as their guaranteed keys to *jannah*. These results confirmed findings from previous literature which were conducted with Muslim parents of children with disabilities (Al-Mosa, 1999; Mirza et al., 2009; Jegatheesan et al., 2010; Alqahtani, 2012).

Whilst religious beliefs and faith provided these mothers with a context offering a sense of meaning, in this study however, and in contrast to much of the previous literature, some of the mothers explicitly argued and contested the idea that *tawahod* is considered an *ibtila* trial or test or a sign of Allah's love to them. This is contrary to a study by Al-Mosa (1999) who explained that Saudi cultural morals regarding disabilities are based on the Islamic faith, and therefore disabilities could be perceived as a punishment for someone or a test of their faith. All mothers in the present study did reservedly dismiss the idea of *tawahod* being a punishment.

The latter finding, which is the refusal of "*tawahod* being a punishment" by mothers is consistent with a study carried out in the rural communities of Egypt where religion plays a dominant role in their entire life specifically in the way people interpret hardship/*ibtila* (Hussein, 2012). Hussein (2012), explained that the respondents in his research did not

perceived the hardships they encountered in a negative light. On the contrary, they perceived hardship (e.g., having an intellectually disabled child) as a way to examine their faith, endurance and their acceptance of God's will.

Another religious explanation offered by many mothers to make sense of autism and cope with the challenges of raising such a child, was the idea that they were chosen by Allah for parenting a child with autism and that this was not a coincidental event. The mothers provided deep and rich narratives which have functioned as a coping strategy to manage the situation in which they find themselves.

One explanation was that Allah gives the person what s/he can tolerate and handle (e.g., strength, patience and determination). They all quoted this *ayah* from the Quran *Surat Al-Baqarah-ayah (285- Allah does not burden a soul beyond that it can bear...286)* as a religious proof attesting to their explanation. Due to such competence which sets them apart from other mothers (i.e., mothers of normal children), they would be able to care and cope with autism. This finding corresponded with previous studies which carried across various faiths by Tarakeshwar & Pargament, (2001), Jegatheesan et al., (2010) and Alariefy, (2016).

A second explanation stemming from Islamic faith was highlighted with many of the mothers quoting a popular proverb in Saudi "*if you see others' tragedies, yours will be eased*". A number of mothers draw upon this and constructed alternative meanings about autism in which they implied that

autism is not the worst thing in life and some people could experience far worse situations (e.g., children with cancer) than parenting a child with autism. By minimising autism and bringing it into stark contrast with more devastating and stressful situations, these mothers tried to elevate their situation to cope better and purportedly accept their situation. This finding was similar to a study conducted on children with disability in Saudi Arabia by Alariefy, (2016) and similar to the finding by Tarakeshwar & Pargament, (2001) on mothers of children with autism from different religious background.

While all of the mothers in this study passionately and emphatically drew upon their religious beliefs to gain a spiritual understanding for having such a child and to cope positively with the ongoing challenging demands of raising a child with autism, there were two returning questions that kept coming back persistently throughout our conversations; “*why do I have such a child?*” or “*why me?*”. These two questions kept lingering in all of the mothers’ narratives and interestingly were persistently asked even after the mothers had offered different religious explanations for their journey with *tawahod*. As a result, some of the mothers set upon a new quest to search for and **understand the deep religious meaning** of having a child with autism in a new light of their faith. These findings were totally juxtaposed to Muslims’ belief in regard to fate and destiny, where Sunni Muslims “*never questioning, only accepting*” of what giving to them by Allah (Jegatheesan et al., 2010).

These findings are novel and in contrast to most previously published literature in this area (Tarakeshwar & Pargament, 2001; Shaked, 2005; Mirza et al., 2009; Marshall & Long, 2010; Alariefy, 2016; Ilias et al., 2017). These previous studies showed various coping themes used by mothers of children with autism from different religious background to generate meanings for autism in their lives and to reduce its challenging impact. They showed how mothers tried to come to terms with autism by both the evolving **cultural and/or religious meanings** they constructed for autism and/or by changing of their coping processes over time to mitigate against the adverse circumstances of living with autism. The finding of this study, in contrast, indicated that all of the mothers asked themselves these two questions, challenging and questioning the will of Allah, whilst concurrently providing and constructing deep and rich religious meanings justifying why they and their family had been given a child with autism.

Previous research has shown that Muslim families in Pakistan who deemed their child's intellectual disability to be due to the will of Allah looked after them as a pious act of faith (Mirza et al., 2009). These families were more likely to consider the condition of their child unchangeable, and so they believed that they had to only take care of the child in the most basic sense (e.g., feeding, washing, cleaning them etc.), as one participant put it "*we don't have to make him get better*" (p. 564), but as a result they would still be rewarded by Allah.

According to Ravindran & Myers (2012), fatalistic beliefs about the child's disability (e.g., being God's will) are more likely to result in parents

accepting their child's condition as fate or destiny and lead to lower expectations for cure or improvements being made from treatment. All of the mothers in this study embraced fatalistic belief towards their child's autism (e.g., Allah's will and fate) which aligned with the two previously stated studies, but differed from them in that many mothers were still hoping and working to cure the child (e.g., I will get him out of *tawahod* and integrate him with the community, *tawahod* world is so fragile and weak and with Allah's will I will get him out of that, sending my daughter to right school with the right intervention will make her a similar to normal children I'm sure of that). This again highlights a more subtle, nuanced and ambivalent interpretation of autism and disability in this culture than has been demonstrated in previous research.

Autism's Impact on the Mother and the Wider Family

Arab culture is characterized by hierarchical, interrelated family relationships with an emphasis on interdependence rather than individualism (Pharaon, 2004; Dwairy et al., 2006). The structure of the Arab family is extended rather nuclear. However, the structural extended family where several generations reside in the same household has evolved in recent generations to more frequent contacts and interdependence between several nuclear families from the same tribe (EL-Islam, 2008). The extended family is the most important institution in Saudi society, therefore strong family ties and connections signify a central aspect in Arab culture (EL-Islam, 2008; Sharifzadeh, 2011). The family in Saudi culture continues to preserve its cohesion in the traditional form, where small families that live away from their

extended family still offer their loyalty and conformity to the eldest and the senior members of the family (Le Renard, 2014; Alariefy, 2016).

Connections within typical Arab families play a vital role in the society since the extended families provide care and support to the young and people with disabilities between them rather than seeking outside services (Yamani, 2000; Sharifzadeh, 2011).

When raising a child with autism within Arab-Muslim culture, a number of factors are undoubtedly going to affect the child, the family and the extended families. As described above, Arab-Muslim culture is a collectivist one and the involvement of extended family members is common and an expected part of family life. Therefore, raising a child with autism is influenced strongly by that culture, its religion and the society. In turn, the child with autism has an impact on both the immediate and extended family.

The findings of this study indicated that each mother endured a unique different (*rehla*) journey within each stage of her overall unfinished journey. Most of the mothers in this study were the first to notice and observe issues with their child's development. They then typically approached their husbands to discuss these observations and concerns. In most cases, the fathers did not agree with the mothers about any of these concerns and insisted that nothing was unusual with the child. They also warned the mothers from talking about their concerns to their in-laws and even to their own family members. This study showed that mothers, and particularly fathers, did not share everything in regard to the child's disability with their families. What was shared was limited and mostly controlled by

the fathers, and sometimes the mothers, for a long period of the child's life. Furthermore, in the Mothers' narratives when they spoke about support and help from their extended family, they did not cite or mention any major emotional, social and financial support concerning the child or the parents. This finding is in contrast with the aspect of Arab culture that values interrelated family relationships and emphasises interdependence rather than individualism.

Unfortunately, I could not find any study exploring this aspect further in previously published literature. This finding speaks volumes against the backdrop of the importance of the extended family in regard to providing care and support to its members in Arab culture. It demonstrated a contradictory aspect to the traditional Arab family framework which is deemed as pivotal to its social culture and has been previously documented in several studies across different regions of Arab culture.

Most of the mothers in this study were not allowed by fathers to seek medical explanations for their children's problems for a number of years. During this time, many mothers felt lonely and unsupported by the fathers' constant denial of the child's disability. These descriptions are consistent with research conducted with Arab American parents of children with disabilities. Donovan (2013) reported that some mothers in her study described experiences with their husbands' rejection of the idea that their children were disabled. In the same study, even after the official diagnosis was made, most of fathers continued to keep their children's disabilities a secret from their families and from others. In addition, most of the fathers in

this study seemed reluctant to take the child with them to any social gatherings and activities or have the child around when they hosted their friends, instead asking the mothers to keep the child at home, away from public eye. Many mothers were sorrowed by witnessing the fathers' embarrassment about their child, especially in public places. This finding is similar to other findings (Shaked, 2005; Crabtree, 2007; Alariefy, 2016; Ilias et al., 2017; Kadi, 2018) and resonant with the narratives of the mothers in this study.

Some mothers in the present study voiced that their husbands had not yet shared their child's disability with their families and asked them to keep it secret. This resulted in keeping the child from visiting his father's side of the family which isolated the child more. In addition, a few mothers would not take their autistic children to visit their families when they had extended relatives gathering or guests visiting, as they felt embarrassed by the child's challenging behaviours in front of those distant relatives from whom the child's disability was still a secret. In addition, some of their extended families required the child's absence in certain occasions or formal gatherings, so the child's disability remains invisible from others. Other extended families, especially from the fathers' sides, stopped completely from asking or checking about the child, leading some of the mothers to say "*it feels he is dead to them*". Some extended family members also prevented some mothers from speaking publicly about the child's disability and exerted their power over the mother's silence for a number of years. This is consistent with several studies of families from similar cultural backgrounds

(Al-Gain & Al- Abdulwahab, 2002; Al Thani, 2007; Al-Kandari & Al-Qashan, 2010; Manor-Binyamini & Shoshana, 2018), where they reported that family members with a disability might be kept hidden from the public and could not be seen in public due to the social stigma associated with disability in the Arab world in general (Al Thani, 2007; Al-Kandari & Al-Qashan, 2010). In addition, they explained how disability in Saudi and Kuwaiti culture has a stigmatization effect on both members of the immediate and extended family resulting in keeping individuals with a disability out of sight. People with a disability in such cultures were commonly perceived as burdensome and shameful (Al-Gain & Al- Abdulwahab, 2002; Al-Kandari & Al-Qashan, 2010; 2007; Alariefy, 2016; Kadi, 2018).

Patriarchy is dominant in Arab culture, whereby fathers rarely engage in the caregiving of their children, including children with disabilities, and see themselves as only responsible for providing the family with financial and material needs (Pharaon, 2004; Crabtree, 2007; Alariefy, 2016). A significant and shared experience of parenting a child with autism mirrored by almost all of the mothers in this study, was the stark absence of the fathers particularly from engaging in the caregiving of the child with autism, which they compared to the minimum role they carried out with other children and everyone else in the family. Mothers reflected upon being responsible for all aspects of the household management, providing all day-to-day caregiving for the other children and their husbands. Their narratives magnified the enormous and exhausted responsibilities they were bearing solely about everything including the nonstop challenges of the child with

autism. In turn, they constantly felt drained and isolated from the whole world and their relationships with their other children were affected and strained. Mothers in this study collectively described their feelings of ongoing sadness and depression, and reported experiencing much higher levels of stress when compared to the fathers. This finding is consistent with several studies conducted across a range of cultures and religious background where mothers commonly reported feeling most of the pressure due to shouldering most of the responsibilities (Konstantareas & Homatidis, 1989; Gray, 2003; Crabtree, 2007; Davis & Carter, 2008; Altieri & Von Kluge, 2009; Aldosari, 2013; Zeina, Al-Ayadhi & Bashir, 2014; Ilias et al., 2017; Alariefy, 2016; Manor-Binyamini & Shoshana, 2018).

From the above, it can be seen that the invisibility of children with autism begins at a very early age, starting with the fathers' resistance, then denials of admitting anything is unusual with the child. It then moves to another phase in which the mothers and the fathers negotiated what to share about autism and with whom, but still in most cases kept it secret from part or all of their extended family, resulting in keeping the child hidden away from others to avoid embarrassment and shame. This theme of the invisibility of the child with autism then enters another phase where the extended family welcome the child but with certain conditions and under limited circumstances or refuse the child's inclusion altogether.

As discussed in the results chapter under the invisibility of autism with the wider society, even a specialist school for autism played its role in maintaining the invisibility of children with autism, holding an official and

formal event devoted to children with autism; without the children and their mothers being invited. The invisibility of the child was then perpetuated by the mothers while they were trying to find a welcoming and accepting space for their autistic children and for themselves, as discussed in the example with the group of mothers who get together and go to a farm to escape ongoing negative social perceptions towards themselves and their children. In doing so another layer of social invisibility and exclusion has been added to already existing deep rooted practices within the family, extended family and society in general. This current finding is novel and no existing research or studies have found or discussed such a fundamental issue which affects the family, the child and the entire Saudi society.

Stigma

The findings discussed in the results under “autism’s impact on the mother and the wider family”, showed that denial, shame, secrecy and embarrassment were strong words used in all of the mothers’ narratives to describe and reflect on their enduring unfinished journey with autism, their children, their families and the outside world. While mothers did not use the word stigma explicitly, all the narratives pointed predominantly towards social stigma. Before discussing further the nature of mothers’ narratives, I will shed some light on stigma, specifically within Arabic context.

Although there is a lack of published literature on disabilities in the Arab world, the stigma associated with disabilities in the Arab culture has been well documented (Al Thani, 2007; Crabtree, 2007; Al-Kandari & Al-

Qashan, 2010; Wehbi Lakkis, 2010). Stigma and social attitudes toward disabilities vary within the Arab societies and usually depend on the severity and the kind of the disability. For example, visual impairments, blindness and deafness are less stigmatised than other disabilities (Bazna & Hatab, 2005; Gharaibeh, 2009; Sharifzadeh, 2011). Severe mental disabilities and mental illnesses are more stigmatised than physical and sensory disabilities (Al Thani, 2007; Gharaibeh, 2009; Ahmead, Rahhal, Baker 2010; Sharifzadeh, 2011).

The negative stigmatisation and the social perceptions associated with autism have changed over the years due to the individualised nature of understanding of disorders (Martin, 2012). Due to such an individualistic understanding of disability, children with autism are perceived as behaving inappropriately by their own choice. Consequently, their parents would be blamed by others for using ineffective parenting styles when raising their children (Fernandez & Arcia, 2004). In addition, they might experience disapproval and criticism from neighbours as they are perceived as being unable to control their children (Gray, 1993; Mak & Kwok, 2010). As a result, it would not be unusual that parents of children diagnosed with ASD feel shame and highly stressed.

Stigma does not only impact the discredited individuals (e.g., autistic individual) themselves, it actually extends to reach individuals who are closely associated with those stigmatised (i.e., family members, caregivers, friends...etc) (Goffman, 1963; Mak & Kwok, 2010). Different studies have reported family members encountering various forms of stigmatisation and

discrimination as a result of their children having autism (Gray, 2002) or intellectual disability (Green, 2003; Hussein, 2012). Additionally, due to the fact that the behaviours of those with autism do not meet the expectations of what is appropriate by the normative group, they are often ignored and avoided (Martin, 2012). For example, when children with autism show behavioural oddities in the form of self-stimulation and inappropriate use of their bodies such as; flapping, rocking, smelling, mouthing objects and finger-gazing, such displays may also expose their parents to different stigmas (Konstantareas & Homatidis, 1989). Thus, stigma is considered one of the major problems experienced by parents of autistic children who commonly experience stigmatisation from others (Baxter, 1989; Volkmar & Chawarska, 2008).

The theory of social stigma was originally developed by Goffman (1963). In his work, Goffman defined stigma as a social identity which was perceived to negatively deviate from societal norms and values. Goffman's work was deemed as instrumental in providing an initial conceptual framework for the understanding and the analysis of stigma (Sulaimani, 2018; Mazumder & Thompson-Hodgetts, 2019). Goffman (1963) delineated three separate forms of social stigma which are essential to conceptualise how stigma impacts members of a society. The first form of social stigma involves physical abnormalities that are referred to with harsh and unsympathetic words. The second is associated with characteristics or behavioural traits which bring negative connotations despite there often being no direct link between the trait and the negative association. The last

form of social stigma is tribal stigma which is associated with linking different identities and people of a larger group to a singular category.

In the case of autism, social stigma might arise from misconceptions, stereotypes, and ignorance of the disorder and those living with it (Martin, 2012; Sulaimani & Gut, 2019). In this study, incidents which the mothers described in their narratives corresponded with Goffman's second definition of social stigma; that is associated with characteristics or behavioural traits. Most mothers in this study expressed their sadness about how Saudi society perceived and treated their children. That included staring at the child in public places or mocking him/her due to their abnormal behaviours. Noticeably, mothers comfortably and unreservedly discussed their concerns regarding the social stigma associated with individuals with disabilities in Arab communities in general and in Saudi community in particular. They also talked about the idea of how the Saudi community still perceive individuals with any type of disability as "mentally retarded/majnoon or crazy". Also, how they were generally looked down upon and ignored.

The most interesting aspect of their narratives was when the mothers talked but cautiously touched upon their husbands' shame and embarrassment about the child's disability. Even when they shared with me their loneliness and frustration with their husbands' roles since the start of their journey, they showed reluctance to elaborate or clarifying any question I asked to follow up. It felt like there was a limit set by them as to when to stop talking about certain subjects with me. This same kind of response was

applied carefully to when the mothers discussed and talked about their own families' perceptions and reactions to their children with autism.

All of the mothers shared various narratives about their family's different arrangements such as; how some families support the mother and the child privately but demanded the child to stay home when there is a big social event or preferred that the disability stayed hidden with the family and never brought up publicly. All of the mothers were very dismissive and sometimes completely ignored any follow-up questions in regard to what they think the reasons behind their family's arrangements were and they would change the subject. When they did expand, the mothers tended to offer a narrative about their family acting this way due to the social stigma already held by the Saudi society towards children with disability. The mothers in this sample clearly showed limits to how far could they comfortably discuss certain sensitive and private issue with me (e.g., their husbands' and families' stands towards disability). I was frequently told that not all family matters would be discussed openly and reminded that certain matters always stay with the family. This reflects the nature of Saudi people as a private and conservative community, where each family guard and protect their own matters and issues. Family honour and pride have both shaped and constructed how Saudi family should be perceived publicly. Consequently, certain family issues would always be concealed and hidden from the public. Even matters related to the research would be kept away from me as a researcher. At the end of the day, in their eyes I am still a Saudi woman who belongs to another Saudi family and the same rules would apply to me.

The Impact of Inadequate and Limited Services

The impact of inadequate and limited services for children with autism can be clearly heard throughout all the mothers' narratives regardless of their educational and social background. All mothers commonly agreed on the limited services existing for their children with autism. They felt schools/centres for autism were very limited and most of the services provided were not satisfactory, but they had no other choices. They also felt that the teachers needed proper training to deal best with the children. All the mothers struggled to get advice from the schools with regard to the child's continuing challenging behaviours, how to deal with the child at home and manage autism in general. The very few schools and centres that existed were usually fully booked and the waiting list could stretch up to 2 years. Mothers also voiced their worries about the expensive annual fees for these schools.

One of the most concerning and worrisome issue discussed openly by all mothers in this study was the lack of services for children with autism after the age of 13 years old. The impact of such a particular concern could be felt and witnessed in all mothers' narratives, where all of them were very emotional and could not control their composure. The only option available to these mothers was sending the child to a boarding school/centre for autism in neighbouring countries such as Jordan or Kuwait. Otherwise families who could afford to do so, would have to employ private teachers and trainers to help with the child's schooling in the house instead of separating the child from their family and sending him/her abroad. All

mothers in this study voiced their deep concern regarding the limited resources to aid them in the parenting of their autistic child and deal with the daily challenges of having such a child. They also cited the limited government support for their children. These findings have been supported by the very limited research conducted in SA on this subject to date (Alnema et al., 2016; Babatin, Alzahrani, Jan, Alkarimi & Jan, 2016; Mashat, Wald & Parsons, 2016).

All mothers' narratives also touched on their future concerns regarding what happens to the child if they die and who was going to look after them. Most of the mothers in this study felt in doubt regarding the future of their child either with immediate or extended family members. In this study one mother reservedly shared with me that to overcome this fear, she set aside some money to secure her autistic son's future in case of any eventuality and appointed a lawyer alongside two family members to oversee this process. She cited that she was not confident that his brothers or sisters would look after him appropriately, and feared that rather they would send him to a mental institution. She mentioned to me that many other mothers with children with autism shared her concerns and fears but due to cultural and family restraints, they could not undertake a similar task. This current finding is original and requires further understanding.

Strengths

This is an original study exploring the subject of mothers' experiences of bringing up a child with autism in Saudi Arabia in great depth; which goes

beyond previous literature. Moreover, it gave a voice to the Saudi mothers as well as to the teachers/staff in the centres/schools for autism. Through both interviews and participant observations methods I was able to see and explore in-depth the views and beliefs of mothers of children with autism and the meanings they constructed with regards to autism. This research also debunks the idea that certain types of research, notably ethnography and qualitative interviews, could not be done in Saudi, albeit any research in such a context could not be conducted without being extremely sensitive to cultural traditions, customs and expectations.

Limitations

Nevertheless, this study is subject to certain limitations, which should be considered carefully when evaluating its findings.

Due to the lack of research in the field of disability in general and autism in particular, with no up to date figures on the prevalence of autism in SA, snowballing sampling was used to overcome the challenges of recruiting mothers of children with autism. Such a method may limit the diversity of experiences and exclude different experiences and opinions of other mothers from different backgrounds. All the mothers included in this study were from the city and quite urbanised. Whilst it is not the purpose of qualitative research to seek to achieve a representative sample, nevertheless, this approach might have missed out on diverse and different lived experiences and opinions from mothers who live in other cities, towns and those living in

rural areas with even more limited services or with no services available whatsoever.

A further limitation is that some centres, schools and hospitals withdrew from or refused to take part in the study, therefore further limiting the potential diversity and inclusion of different experiences and opinions.

There were issues around access at the beginning of the study, but once I was immersed during the participant observation, I then had better access to the mothers once they started to trust me and decided to work with me. Being a native Saudi myself enabled access and facilitated trust but could have possibly precluded me from being totally neutral. Being Saudi and doing research in Saudi opened doors but it might also have led to some blind spots. Alternatively, having been living away from my country for several years, some of the cultural familiarities could easily have escaped my notice.

Fathers are very important within the family structure in Saudi especially being the dominant family figure in this culture, with fathers having the final say on everything. Whilst this study enabled the usually unheard voices of mothers to be heard, I was not able to elaborate on fathers' own experiences and opinions. Including them is important but due to cultural traditions and restraints, recruiting them proved to be challenging. Additionally, given the fact that the majority of the participants in research related to Arab parents of children with special need are commonly mothers, including this study, it is vital that future research should address the lack of

male participants and include fathers from the Arab community. This will allow researchers to gain different and richer perspective from fathers' experiences and understandings which are generally absent in the current literature (e.g., themes related to father-child connections and relationships or themes ascribed to the experiences that are limited to males in Arab Muslim cultures). More importantly, it will help to identify differences as well as similarities between the parents, mothers and fathers, in their lived experiences of bringing up a child with autism.

There were some difficulties and challenges in different stages associated with the translation of the material from English to Arabic and then back into English. Every effort was made to ensure that meaning was retained and properly conveyed and many reliability and validity checks were carried out on the data through the use of bilingual researchers and therapists. However, there may nevertheless have been some degree of detail that was lost in the translation process.

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Appendices

Appendix 1: UCL ethical approval

UCL RESEARCH ETHICS COMMITTEE
GRADUATE SCHOOL OFFICE



Dr Simon Dein
Mental Health Sciences Unit
UCL

28th April 2014

Dear Dr Dein

Notification of Ethical Approval

Project ID: 4986/001: Ethnographic study of the religious coping forms of mother's experiences of bringing up a child with ASD in Saudi Arabia

I am pleased to confirm that your study has been approved by the UCL Research Ethics Committee for the duration of the project i.e. until April 2015.

Approval is subject to the following conditions:

1. You must seek Chair's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form'.

The form identified above can be accessed by logging on to the ethics website homepage: <http://www.grad.ucl.ac.uk/ethics/> and clicking on the button marked 'Key Responsibilities of the Researcher Following Approval'.

2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. Both non-serious and serious adverse events must be reported.

Reporting Non-Serious Adverse Events

For non-serious adverse events you will need to inform Helen Dougal, Ethics Committee Administrator (ethics@ucl.ac.uk), within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair of the Ethics Committee will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Reporting Serious Adverse Events

The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.

On completion of the research you must submit a brief report (a maximum of two sides of A4) of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.
With best wishes for your research.

Yours sincerely



Professor John Foreman
Chair of the UCL Research Ethics Committee

Cc: Taghrid Al Qunaibet, Applicant

UCL Research Ethics Committee, c/o The Graduate School, North Cloisters, Wilkins Building
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www.ucl.ac.uk/gradschool

Appendix 2: Topic guide in English

Topic Guide:

Demographic Information:

Name:

Mother's age:

Mother's education:

Mother's marital status:

Father's age:

Father's education:

Number of children:

Child's age:

Child's gender:

Age when problem was noticed:

Age when diagnosis was made:

Questions:

1. Tell me about your child problem?
2. How would you label their problems?
3. What do you think is causes his/her problems?

Probe question:

Are any particular religious causes of this?

4. What particular aspects of your child illness or problematic?
5. In what ways have you tried to cope with your child's problem? Or what of anything help you cope with your child's-problem?

Probe question:

Is religious coping (e.g., prayers, reading Al-Quran, go to religious healers) helping?

How have they been helpful? Or what aspects of religious coping?

6. Which ways of coping have not helped you to deal with the problem of your child?
7. How have they hurt you?
8. How does your child illness make you feel?
9. What helps have you sought for your child illness?
10. What concerns do you have about your child future?
11. How do you feel about these arranged educational events?
12. What services or help are missing here and you need them?

Appendix 3: Participant information sheet

Information sheet

Introduction and Research Topic

My name is Taghrid ~~Algunaibet~~. I am a PhD student at University College London UCL. My research project is looking at the coping strategies, in particular religious coping of mothers raising an autistic individual in Saudi Arabia. Specifically, my study will examine the function roles of religion as a coping resource and how religion helps you to understand, deal, and cope with having a child with autism.

I want to know what problems you may be facing and how do you cope with them.

I want to learn more about your experiences in different situations and events.

The Interview

I would like to interview you for 1-2 hours and ask you questions about your son/daughter with autism. These interviews will be tape-recorded and will be anonymously written-up. The recordings will be deleted following transcription. All your answers will be confidential. The things I write down will be entered in a computer without your name on it and nobody will have access to it except me.

Consent

I would like your permission to attend with you any medical appointment with or without the presence of your child in regards to diagnosis or treatment consultation. Also, your permission is needed to accompany you to any religious ceremonies or educational events for autism. In all the above events, I will just go with you and observe the event taking place and I will not be writing or recording anything. Attending these events with you will enable me to understand your experience deeply. If, for any reason, you do not wish for me to attend any event with you then you will have opportunity to disclose your preference.

You can decide if you want to take part or not. You don't have to take part. You don't have to give a reason. Whatever you decide this will not change anything for you son or daughter with autism. You can stop taking part at any time. You don't have to tell me why.

As a mother, you will also be providing consent on behalf of your child to be present during the clinical appointments/religious events where interviews may take place. Children are not legally able to provide consent. However, I will work on the basis of assent, which is the expression of approval of my presence, in order to ensure that your child is comfortable. If the child express disapproval to my presence whilst observing the appointment ~~the~~ observation/interview will be terminated. The notes I will be making will be observations of mothers only, and not your children. Thank you

very much for taking the time to read this information sheet (or to have this read to you). Please take your time to think things over before deciding to take part or not. If you want to talk or ask more questions please do not hesitate.

My email is:

[REDACTED]
[REDACTED]
[REDACTED]

Appendix 3: Consent form

Consent Form

Name of Researcher: Taghrid Alqunaibet
Contact Number:

Participant reply form – please complete if you are happy for the research investigator to contact you.

Title of Study: Ethnographic study of the religious coping forms of mother's experiences of bringing up a child with ASD in Saudi Arabia.

- | | Please tick
the box |
|---|--------------------------|
| 1. I confirm that I have read and understand the research information sheet for the above study and have had the opportunity to ask questions. | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my son/daughter care or legal rights being affected. | <input type="checkbox"/> |
| 3. I understand that the above researcher from the University College London UCL is working on the project will have access to my personal details. | <input type="checkbox"/> |
| 4. I understand that any data or information used in any publications which arise from this study will be anonymous | <input type="checkbox"/> |
| 5. I understand that all data will be stored securely and is covered by the data protection act. | <input type="checkbox"/> |
| 6. I agree that the researcher can contact me on the below telephone number to arrange an interview at a time and location to suit me. | <input type="checkbox"/> |
| 7. I agree to my interview to be audio taped | <input type="checkbox"/> |

Name of Participant

Date

Signature

Contact telephone number:

Appendix 5: Topic guide in Arabic

دليل , الموضوع:

المعلومات الديموغرافية:

الاسم:

اسم الام:

التحصيل العلمي للأم:

الحالة الزوجية للأم:

عدد الاطفال:

عمر الطفل:

جنس الطفل:

عمر الطفل عندما لوحظت المشكلة:

عمر الطفل , عندما تم التشخيص:

الأسئلة

اخبريني عن مشكلة طفلك؟ .

كيف تصنفين مشاكل طفلك؟

ماذا تظنين سبب مشكلة طفلك؟

سؤال استطلاعي:

اهل هناك اي اسباب دينية معينة لهذا؟

هل من جوانب معينة من مرض طفلك او اشكاليات؟

كيف حاولت التأقلم مع مشكلة طفلك؟ او ما الذي ساعدك على التأقلم مع مشكلة طفلك؟

سؤال استطلاعي:

هل ساعدك التأقلم الديني (مثلا الصلاة، قراءة القران، او الذهاب الى معالج ديني)

كيف ساعدتك هذه الوسائل؟ او اي جوانب من التأقلم الديني؟

اي من وسايل التأقلم الديني في العامل مع مشكلة طفلك لم تساعدك؟

كيف اضرتك؟

كيف تشعرين ازاء مرض طفلك؟

ما هي المساعدات التي يحتني عنها؟

ما هي مخاوفك تجاه مستقبل طفلك؟

ما هي مشاعرك تجاه هذه الاحداث التربوية المنسقة؟

ما هي الخدمات او المساعدات المفقودة هنا و التي انت بحاجة لها؟