

JOURNEY TOWARDS HOPE WITH HOPE:
AN INTERPRETATIVE PHENOMENOLOGICAL
ANALYSIS OF MALDIVIAN MOTHERS RAISING
CHILDREN WITH AUTISM

FARZANA SHAUGEE

FACULTY OF ARTS AND SOCIAL SCIENCES
UNIVERSITY OF MALAYA
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ORIGINAL LITERARY WORK DECLARATION

Name of Candidate: Farzana Shauggee (Passport No: [REDACTED])

Registration / Matric No: AHA100053

Name of Degree: DOCTOR OF PHILOSOPHY

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JOURNEY TOWARDS HOPE WITH HOPE: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS OF MALDIVIAN MOTHERS RAISING CHILDREN WITH AUTISM

ABSTRACT

Autism is a lifelong developmental disorder. The role of the main caregiver, in particular, the mother is critical in the treatment process. A phenomenological study was conducted to get an in-depth understanding of the experience of Maldivian mothers raising children with autism. A purposive sample was selected among Maldivian mothers who have been raising a child diagnosed with autism. The mothers selected were those who have at some point in their children's life been in contact with the speech pathologist and therapist. In-depth interviews were conducted with six Maldivian mothers raising children with autism. There were four core findings of the research that has implications for clinicians who work with children with autism. First, the mother's 'maternal intuitive diagnosis', sensing of differences in their children's development at a very young age. Second, the pattern of the grieving process that all mothers go through when their children are diagnosed with autism as well simultaneously going through the treatment process like a 'warrior'. Third, the mother's acceptance of one's child having a long-term disability such as autism as one's destiny in a faith-based positive way. Fourth, ways in which the mothers go through a process of 'maternal metamorphosis, a transformative process in which the mothers change and adapt their self in order to take care of their autistic children. This research will be beneficial to clinicians treating children with autism or any such long-term disability with implications that the findings can be used by the clinicians in formulating a better process of diagnosis, counselling, treating and empowering the mothers (caregivers) through their journey of raising their autistic children.

Key Words: phenomenology, autism, mothers, intuitive maternal diagnosis, maternal metamorphosis

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ABSTRAK

Austisme merupakan satu kecacatan perkembangan seumur hidup. Peranan penjaga utama, khususnya ibu, adalah kritikal di dalam proses rawatan. Satu kajian fenomenologi telah dilakukan bagi mengumpulkan pemahaman terperinci pengalaman sekumpulan ibu-ibu di Maldives yang membesarkan anak-anak autisme. Satu sampel yang dipilih secara bertujuan telah dilakukan di dalam kalangan para ibu yang mempunyai anak autisme. Para ibu yang terpilih merupakan mereka yang pada satu tahap tertentu dalam kehidupan anak mereka telah berjumpa dengan ahli terapi dan patalogis pertuturan. Temubual mendalam telah dilakukan ke atas enam orang ibu warganegara Maldives yang mempunyai anak autisme. Terdapat empat dapatan utama kajian ini yang mempunyai implikasi kepada ahli klinikal yang bekerja dengan kanak-kanak autisme. Pertama, “diagnosis intuitif keibuan” yang dialami oleh para ibu dapat mengesan perbezaan dalam perkembangan anak mereka pada awal usia. Kedua, pola proses kesedihan yang dilalui oleh ibu-ibu apabila mendapati anak mereka mengalami autisme dan pada masa yang sama perlu melalui rawatan adalah seperti “pahlawan”. Ketiga, penerimaan ibu yang anak-anak mereka mengalami kecacatan kekal jangka masa panjang dilihat sebagai takdir mempunyai kaitan dengan kepercayaan mereka. Keempat, cara bagaimana ibu-ibu tersebut melalui proses metamorfosis keibuan merupakan satu proses transformasi di mana mereka berubah dan menyesuaikan diri agar boleh menjaga anak-anak mereka yang autisme. Kajian ini bermanfaat untuk ahli-ahli klinikal yang merawat kanak-kanak autisme; iaitu dapatan-dapatannya boleh digunakan oleh mereka di dalam menggubal satu proses diagnosis kaunseling, rawatan dan pemerkasaan yang baik untuk para penjaga yang membesarkan anak-anak autisme mereka.

Key Words: fenomenologi, autisme, ibu-ibu, diagnosis intuitif keibuan, metamorfosis

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CHAPTER 1 : BACKGROUND OF THE STUDY

“Allah does not burden a soul beyond that it can bear” – Quran 2:286

“Indeed Allah is with those who can patiently endure” – Quran 8:46

“So Verily, with the hardship, there is relief” – Quran 94:5

1.1 Introduction

The researcher begins this chapter by introducing the area on which the research is based on, which is Autism Spectrum Disorder. Then, it is followed by the problem statement, the objective, the research question and the significance of the study. In this section, the researcher introduces the research context with an overview of the methodology and the operational definitions. Finally, the chapter will be concluded with the explanation about the scope and the limitations of the study.

1.2 Autism Spectrum Disorder

Autism, Autistic Disorder or Autism Spectrum Disorder (ASD) are different terms referred to what is commonly called ‘autism’ (Dillon, 1995; Stone & Digeronimo, 2006). According to Lin et al., (2010) and American Psychological Association (2000), autistic spectrum disorders include Autistic Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder–Not Otherwise Specified (PDD–NOS). For the purpose of easy reading and writing, the word ‘autism’ is used throughout the thesis referring to the ‘autism spectrum disorder’.

Autism, Asperger Syndrome, Pervasive Developmental Disorder–Not Otherwise Specified (PDD–NOS) or atypical autism is interchangeably used among professionals. As stated in Lin et al., (2010), all the above names are referred to children who fall under the umbrella term of Autistic Spectrum Disorder. They are

known as autistic children or children with autism. For the purpose of this research, children who are considered as autistic are those children who have received any of the diagnosis above, and they have been diagnosed by at least one of the professionals involved in diagnosing and treating children with autism.

The three most prominent impairments common to all individuals with autism are impairments in social interaction, inability to communicate and impairments in patterns of behaviour (Dillion, 1995). Stone and Digeronimo (2006) further elaborated on these impairments by stating that Autistic Disorder ‘... is characterized by a pattern of severe impairments in three areas; difficulties interacting with others in a reciprocal way, impaired language and communication skills, and a repetitive and restricted range of interest and activities’ (p. 7). Signs of autism become apparent during early years, usually before the age of three. Some children may not show any symptoms until two years old (Woodgate, Alteah & Secco, 2008). Stone and Digeronimo (2006) also stated that symptoms of ASD would emerge before the age of three years. Regarding gender, boys to girls ratio of autism are 4:1 respectively (Stone & Digeronimo, 2006).

Although autism does not have a definite cure, there are some intensive treatments that can help improve autistic children’s quality of life by reducing the impact of impairments (Woodgate et al., 2008). The most heard treatment programs come under Discrete Trial Training (DTT) or Applied Behavior Analysis (ABA) programs. Other therapies utilised in treating children with ASD include speech and language therapy, occupational therapy, relationship development intervention (RDI), treatment and education of autistic-related communication-handicapped children (TEACCH), and Floortime or Developmental Individual-differences (DIR). Ideally, children with autism need help from a multidisciplinary or a trans-disciplinary team

consisting of paediatricians, clinical psychologists, psychiatrists, educational specialists, occupational therapists, speech and language therapists, and physical therapists in the process of diagnosis and treatment (Siegel, 2008).

Lin et al., (2010) quoted the American Psychological Association (2000), which stated that children who fall under autistic spectrum disorders have a life-long developmental disability. According to Rahman (2005), in addition to it been a life-long developmental disability, it also affects people in different ways. In essence, autism not only affects the children but also has an impact on the families. A study done in a western Canadian province in 2008 had found that parents had to 'fight all the way' in getting the system to work for them. The parents, majority of them mothers, had to fight the system literally to get what their children needed. To be able to get through the system, parents had to become strong, get themselves educated, be more assertive and direct and as well as even educate others in the system to make themselves heard (Woodgate et al., 2008:1081). In fact, they had to become their advocates. Indeed, it is easy for us to feel sympathy for the parents and children, but sympathy alone cannot help people trying to battle a lifelong disability such as autism. Parents would need appropriate and necessary support from professionals from the very beginning; that is from the moment the parents face their children's diagnosis, through on the treatment process and beyond (Barbosa, Chaud & Gomes, 2008; Benderix, Nordstrom & Sivberg, 2007).

According to Harris and Weiss (2007), there are limited professionals who understand autism even in some parts of the United States, as well as some other countries of the world. As well in some countries, specialised services are virtually non-existent. Therefore, the challenges and the difficulties faced by parents of children

with autism can be manifold especially in smaller and less developed communities as there are little awareness and limited resources. Sometimes, even if the resources may be available in the given country, parents can still experience ups and downs within the family, their immediate community and even the wider society due to lack of awareness and support.

The Canadian study by Woodgate et al., (2008) mentioned above has also found that the lack of understanding of autism in the society leads to stigmatisation and isolation of parents and their children to the extent that parents felt that they do not even have a life. Thus, again it is critical that the professionals be more receptive to the parent's needs and join forces with the parents in the process, to get their voices be heard by the authorities and the society to be able to meet the needs of children with autism.

The complexities of autism can have devastating effects on parents of children with autism. The parents' role, especially of the main caregiver, the mother is very significant because they are the core people in the children's daily lives. Hence, parents need to be supported in the best possible way by the state, professionals and the wider community. The main caregiver's role can be assumed to be even more important than a professional. They are what the researcher would like to call the 'co-partners' in the treatment process, the regular person who takes care of the child as well as the one who meets all relevant professionals in the treatment team. Siegel (2008) says '...there is no team unless parents are on board; parents are the key ingredient of any treatment plan' (p .53). Thus, support for the parents of children with autism cannot be overlooked or underestimated.

It is also important that the professionals, family, friends and others who are unaware of the impact of autism on the children and their parents are educated (Woodgate et al., 2008). Parents of children with autism need to be not only educated regarding the treatments that the children need, but they also need to be supported and helped even at the emotional level. Studies on experiences of mothers of children with different disabilities show that appropriate psychological support is a necessity for the family of a child with a disability (Barbosa et al., 2008).

Social stigma around autism can also play a significant role in parents' ability to get their children out into the social world. Taking the child into the social world and intensively trying to get the child involved in communication and socialisation is a core area parents need to work on. The findings of the study done by Woodgate et al., (2008) showed that parents felt that society devalues the lives of children with autism and as a result, they felt stigmatised and isolated. The parents of this study voiced that they felt isolated from the 'normal' way of life. They felt a certain sense of disconnection from the family. The study concluded that the product of the sense of isolation left the parents with a diminished sense of hope (Woodgate et al., 2008:78).

A book entitled *Ibrahim: where in the spectrum does he belong?* (Rahman, 2005) was written by a mother of a child, born in England who falls within the spectrum disorder. The author mentioned the difficulties she has encountered raising her son with autism. Rahman's challenges include difficulties faced within her family, her immediate Bangladeshi community and even the wider society in the United Kingdom. Similar findings were shown in more recent studies done in some other developed countries. To summarise, it is clear that the situational factors of a given

country or community in which they belong to can have a significant impact on the families raising their children with autism.

In recent years, countries and institutions are repeatedly exploring ways in which to help parents and children with autism, by increasing the support services, shifting attitudes and helping them to adapt to the normal life (Beatson & Prelock, 2002; Midence & O'Neill, 1999). To be able to support the parents of children with autism, it is important that one has a good understanding of what the experience mean for them. Such an understanding of the parents' experiences can guide to deliver proper and meaningful support, whether it is by the government, by a professional, or even by the society. Woodgate et al., (2008) suggest that professionals working with children with autism and their families should also be made aware of what the parents feel and the meanings of their experiences to them.

Hence, the need for us, the practitioners in the field of autism, to understand the lived experience of parents raising children with autism is what interested the researcher in the area and topic of this research. This study aims to explore the life experiences of Maldivian mothers raising children with autism. No such study has been carried out in the Maldives to the researcher's knowledge in the area of this current research. Hence, the findings of this study are expected to widen our understanding of the Maldivian mothers raising children with autism.

1.3 Problem Statement and Research Questions

Maldives is a developing country going through an evolving and a transitional period in its political system over the past two decades. The first democratically elected

president was elected in 2008. As can be expected, the interim period has its share of difficulties. The newly formed democracy came with several political parties that were formed among a small population of about less than half a million, a culturally and socially close-knit population.

The social security, gender and the health system also had gone through a transitional period with a new health insurance scheme. Among the areas that are challenged in the health system is the lack of specialists in the field of disabilities; especially within the state governed services in sectors such as clinical psychology, speech pathology and social workers to name a few. For example, currently the country has only three speech pathologist and language therapists, less than five clinical psychologists and just one occupational therapist that are registered and practising in the country (Ministry of Health, Maldives; n.d). Among this, the occupational therapist is an expatriate, and at the point of this research, there is not a single local personal trained in occupational therapy. Over the past decade, there is a rapid increase in autism in the world (Feinstein, 2010). Through the researcher's professional experience as a practising speech pathologist and language therapist in the Maldives for the past 25 years, Maldives also seems to be facing the issue of a rapid increase of children with autism in recent times, especially within the past decade.

As stated above, autism is a life-long developmental disability. Due to this nature, caring for children with autism can be an enduring and a challenging process. The challenges encountered by the families can depend on various factors such as children's severity of the condition, their gender, age, parental expectations, societal awareness and available services, to name a few.

Studies in different parts of the world have looked into experiences of parents and caregivers of children with autism, their needs and variances across different individuals, societies and even various ethnic groups. For example, a study done in Hong Kong showed individual differences in dealing with different types of stigma such as courtesy stigma and affiliate stigma with families with children with autism (Mak & Kwok, 2010).

The expectations parents and caregivers have from the society, the support they receive from various sources can vary depending on certain individual factors such as parents' education, gender and parental age and their children's gender and age (Papageorgiou & Kalyva, 2010). The differences in variance in the ability to cope and the coping strategies also have differences across different ethnic groups and cultures (Lin et al., 2010).

The research has been inspired as a result of the researcher working as a speech pathologist and language therapist for over 25 years. The researcher has dedicated her entire career as a clinician treating various disabilities including autism. Over the past few years, several reasons have compelled the researcher towards the topic of research, autism, therapy and parents and their families.

Firstly, the experience has lead the researcher to believe that to help children with complex disorders such as autism by the professionals; it must collaborate. The effort should be integrated; that is the effort of the professionals must be incorporated with the parents, the primary caregivers. In other words, a holistic support system must include the parents, families, professionals and the significant other in the wider society.

Secondly, the researcher also believes that for any given human to be able to help someone else in a difficult situation, such as helping your children with autism, the parents or main caregivers must be supported by others. Such support is critical to minimise the amount of stress of the parents and caregivers, which is essential for the efficacy of the caregiver's role. The more the person is content and equipped with, the better the chance of giving quality support to others. Thus, parents need to be helped to decrease their parental stress which is an effective way to help their children through them (Duarte et al., 2005).

Thirdly, for children with a life-long disability such as autism, their parents play a fundamental role in delivering whatever the service that the relevant professionals are trying to address. They are like mediators, assistants without which the work cannot be completed. Siegel (2008) states that parents are an essential ingredient in treatment that the professionals cannot do without.

During the many years of the researcher's professional career, the researcher has experienced and come to believe that 'mothers' play the leading caregiving role in children with autism and other developmental disabilities in the Maldives. This pattern is not uncommon in other parts of the world. Past literature shows that there seem to be some studies that are mainly directed towards mothers of children with autism and other long-term disabilities. Also, when research is conducted on parents, the majority of participants of such research also happen to be mothers (Beatson & Prelock, 2002; Duarete et al., 2005; Lin et al., 2010; Papageorgiou & Kalyva, 2010; Woodgate et al., 2008). According to Duarte et al., (2005), the role of the mother in the treatment of autism is essential.

The primary focus of the research is based on the fact that raising children with autism is a challenging life-long journey. The mother's experience of the process of coping and raising children with autism can have numerous challenges. There may be several similarities as well as differences in their lived experiences. Possibly the problems can be multiple in less developed communities, such as the Maldives, where there are limited awareness, professionals and holistic support services. This study was conducted to get an in-depth understanding of the experiences of Maldivian mothers raising children with autism, which can enhance a more meaningful comprehensive model of treatment and support for children with autism. It answers a critical question: what is the lived experience of the Maldivian mothers raising children with autism?

The aim of the study is to explore the experiences of the Maldivian mothers raising their children with autism. The central research question is what are the lived experience of the mothers raising children with autism and how do the mothers make meaning of their experiences in raising their children with autism? This central question leads to getting answers for secondary questions such as, what are the different challenges faced by the mothers in raising their autistic children? Were they able to overcome those challenges and if so how did they overcome them? Were there difficulties that they could not manage and if so why and what are they?

1.4 Purpose and Objectives of the Study

The purpose of the study is to explore the lived experiences of Maldivian mothers raising children with autism. The objectives of the study are:

- 1) To understand their perceptions and the meaning they ascribe to their lives of having to raise their children with autism,
- 2) To get an in-depth analysis of the essence of the participants lived experience as they have lived it; and,
- 3) To propose a holistic social support system for families raising children autism.

1.5 Scope of the Study

The scope of this study is the meaning of the experience the mothers ascribe to raising children with autism. In other words, the research hopes to get an in-depth understanding of the mothers' experience as they mean and have experienced and lived it.

According to Smith et al., (2009), the reality that humans' consciousness of self is evolving and this changing of self is connected to how we experience and make sense of the world. Thus, in other words, the meaning one gives to the phenomenon is based on how one experiences that particular event. The phenomenon, the essence and the meaning of motherhood will be based on what the mothers go through in raising their autistic children.

The experiential nature of constructing the meaning of motherhood is connected to existentialism which is a philosophical concept that assumes the essence of the meaning human experience of any phenomenon is based on one's experience. Smith et al., (2009) in referring to Sartre's description of existential phenomenology, say that Sartre emphasised that we (humans) are caught up in projects in the world that facilitate meaning-making. He says that "*...while we have self-consciousness and seek*

to mean, this is an action-oriented, meaning-making self-consciousness which engages with the world we inhabit” (p. 19). According to Smith et al. (2009), it refers to the reality that humans’ consciousness of self is evolving, and this changing of self is connected to how we experience and make sense of the world.

Thus, the meaning one gives to the phenomenon is based on how one experiences that particular phenomenon. When seen through the lens of existentialism, the phenomenon of motherhood, the essence of motherhood will be based on what the mothers go through in raising their autistic children. From this perspective, what it means to be a mother of an autistic child will be different from a mother of a child without autism. Furthermore, raising an autistic child in a Western developed social context can be entirely different in meaning from raising such a child in a less developed and a culturally different societal context like the Maldives.

Hence, by understanding the mothers’ experience, how they make meaning of motherhood, relationships, marriage and their status in society changes and evolves in the process of raising autistic children. The concept of self, a mother’s joy of having a baby, for example, would likely transform in the process of raising autistic children. This study is an attempt to capture the meaning and ways of being for mothers with autistic children. The scope of the survey thus explores the mothers’ world of intuition, relationships, struggles, emotions and worldview in raising autistic children.

1.6 Significance of the Study

The importance of the study is manifold. Firstly, there is little research done on the realities of mothers raising children with autism in small communities such as the

Maldives. Developing countries, such as the Maldives, have limited awareness, limited professionals and limited specialist support services for children with autism. Thus, the evidence from this study could help to guide Maldives and other similar small nations to get a better understanding of mothers raising children with autism to plan for better services for the autistic children and their families.

Secondly, as for the researcher's knowledge to this day, there are no such in-depth studies done in the Maldives that have looked into the experiences of mothers raising children with autism. The findings of this study can give a thorough understanding of what and how mothers go through their journey of raising their children with autism. Thus, this study's findings can be new knowledge that can bridge the gap in the service system and further facilitate planning a more holistic support system for the children and their mothers in their journey with autism.

Thirdly, this study can guide to help professionals like the researcher and the other members of the multidisciplinary team of specialists who work with children with autism and their families, to have a better understanding in order to embrace their needs and realities of raising children with autism so that the help and support is more tuned to the individual needs of the families and the children with autism.

Fourthly, this study also highlights the level of support available within the Maldives as well as identifies limitations within the medical, therapeutic and social support services that need to be made available towards a holistic support system for the mothers and their children with autism. Thus, the information from this study, the experience of mothers raising children with autism, can be used as a guide for the professionals, the government, the NGOs, and also by the community to help and form

a more appropriate holistic support system for the children and the families with children with autism in Maldives.

Finally, the researcher hopes this study can also give some insight in general to other communities similar to Maldives where there are limited awareness and services available for the children with autism and their families.

1.7 Organisation of Chapters

This thesis consists of five chapters. This chapter, Chapter One is the general introduction to this research study. Chapter Two is the review of relevant literature which is related to this study. Chapter Three is the methodology section which gives a detail description of Interpretative Phenomenological Analysis (IPA) and why it is chosen as the analytical framework for this research study, followed by the role of reflexivity, the context, participant selection, data collection, data analysis and ethical consideration of the research. Chapter Four presents a detailed analysis of the findings of the study. Finally, Chapter Five consists of the discussion of the key findings of the study with relevant literature. The results are also explored in connection with some theoretical perspectives that may explain the findings and also offer the researcher's interpretive viewpoint on the findings.

CHAPTER 2 : LITERATURE REVIEW

2.1 Introduction

This chapter reviews the existing literature related to the topic of research and experiences of mothers raising their children with autism spectrum disorder. First, the researcher informs the reader on autism spectrum disorder and its prevalence, and then followed by literature on various forms of treatments available for children with autism. Then, the researcher will shed light on the challenges faced by caregivers of children with autism followed by institutional and societal support services that are considered as important for the caregivers raising children with autism. Finally, the researcher conceptualises the framework for understanding the experience of mothers raising children with autism as a ‘journey’; a journey in progress with several phases as themes that are of significance. They are: (1) obtaining a diagnosis, (2) several mixed emotions at the point of the diagnosis, (3) getting treatment for the children, (4) adjusting to family life, (5) coping with the outside world (society) and (6) the role of ‘hope’ in their ‘journey’ of raising children with autism.

2.2 Autism and Its Prevalence

According to the National Autistic Society (2016), autism or autism spectrum disorder is a developmental disorder that affects the way the brain processes information and it is complex in nature characterised by severe impairment in communication, socialisation and behaviour. The degree of the disabilities varies from individual to individual depending on the severity (Leonard et al., 2010). An individual falling within autism spectrum disorders has a lifelong disability (Rahman, 2005). Due to this

permanent nature, the disease can be seen at varying levels of severity as well as is present in some form throughout the child's life (Dillon, 1995).

Autism does not have a complete cure and autistic children become autistic adults (National Autistic Society, 2016). A single or an exact cause of autism is still unknown. The life-long nature of the disability without a definite cure has become an increasing concern for the health and education service providers in both the developed and developing countries. Parents of children with autism are constantly fighting the battle of searching for a cure or treatment for their children. Like all disabilities, autism has also become a major area of social concern mainly because the key features of autism include severe impairment in communication, socialisation and behaviour (Leonard et al., 2010).

Apart from clinical treatment of children with autism, addressing familial and social issues related to supporting autism and helping their parents are important areas of concern. Hence, increasing number of researchers are studying into the lived experience of caregivers of children with autism in order to understand and find ways to support them holistically. Such research highlight specific issues around autism such as the challenges faced by parents and caregivers (Jardine, 2008) to find possible solutions for the challenges faced in raising children with autism (Batman, 2011).

The prevalence of autism has been rapidly changing over the past several decades. It is reported to be as high as 1 in every 150 children (Hamilton, 2000). Sun and Allison (2010) cited Baird et al., (2006), a much later prevalence study on autism in the UK reported a figure of 116.1/10,000. This prevalence is comparatively much

higher than of about 2/10,000 children in the 1970's, as reported by Kawamura, Takahashi and Ishii (2008 in Sun and Allison, 2010).

There have been extensive research and debate into finding the cause of autism over the past several decades. Major areas of research have focused on areas such as genetics, environmental factors, gene-environment interaction, brain research, etc. (Feinstein, 2010). As stated in a book by Feinstein entitled *A History of Autism: Conversations with the Pioneers* (2010), the closest he got to an answer to this question came from Professor Leon Eisenberg who has said “...*the failure to find a single cause that shows up in autistic children suggests there are multiple causes*” (p. 266).

The issue of whether autism is truly increasing and can be viewed as an epidemic have been debated. The debate of finding a reason for the increase in the prevalence of autism has been a topic of discussion since 1990's (Feinstein, 2010). Some believe there is no real growth and puts the reason down to better diagnostic criteria, while others differ in their belief. Those people who believe in an actual rise of autism rather than believing in the possibility of the more sophisticated diagnostic criteria point to some environmental factors as the culprit; though with little scientific backup (Feinstein, 2010).

A study was conducted by Leonard et al., (2010) to get an answer to this question - ‘Is there a real increase in prevalence of autism?’ concludes that certain issues can partly explain the increase. The study stated that the changes in the diagnostic criteria and some other related factors such as reduction in age at diagnosis, improved case ascertainment, societal and cultural influences and the phenomenon of diagnostic substitution could account for the increase in the prevalence. But on the

other hand, it does not yet fully explain the increase. Thus, the paper suggests that the question remains to be answered regarding how much of it is a real increase.

The National Autistic Society (2016) states in the section ‘our position on the causes of autism’ that “...*many experts believe that the pattern of behaviour from which autism is diagnosed may not result from a single cause. There is substantial evidence to suggest that autism can be caused by a variety of physical factors, all of which affect brain development*” (para. 4). Furthermore, National Autistic Society (2016) added that there is an indication of genetic factors that contribute to forms of autism.

2.3 Treatments That Are Available for Autism

A complete cure for autism is still not known (IAN, 2016). But this does not mean that there are no treatments that can help the children with autism. Different treatments that are available for children with autism are discussed below. These include medical, therapeutic and some secondary treatments such as special diets and supplements. Out of these three methods, the most efficient treatments come in the form of therapies such as speech and language therapy, behaviour therapy, occupational therapy, etc.

As stated in the previous section, the exact cause of autism is unknown and also there seems to be no known cure for autism either. Similarly, there appear to be no clear cut answers to the question of what is the best treatment for autistic children. Possibly, due to the various impairments associated with autism, the treatments are also varied. Several specialists make up the team involved in treating autism. Similarly, there are different types and methods of treating autism. The clinical

specialists involved and the types and methods of treatments fall under two broad headings which are discussed below.

2.3.1 Types and methods of therapies for autism

Therapies for treating autism involve a multidisciplinary or a transdisciplinary team consisting of multiple clinical specialists in related fields. The team generally consists of speech and language therapists, clinical psychologists or behaviour therapists, occupational therapists and physical therapists and/ or social workers (Dillon, 1995; Hamilton, 2000; Stone & DiGeronimo, 2006; Barbera & Rasmussen, 2007; Jepson & Johnson, 2007; Siegel, 2008; Feinstein, 2010; Connolly, 2015).

2.3.1.1 Behavioural-based treatment

The most recognised and successful treatment method till to date is known to be based on Applied Behaviour Analysis (ABA) (Siegel, 2008). Verbal Behaviour (VB) approach or Verbal Behaviour Approach (VBA), which is a treatment method used by speech and language therapists in working with autistic children's speech and communication. This approach rooted from B.F. Skinner's Verbal behaviour analysis is a recognised and a successful method of treatment of children with autism, in particular for those children with minimal or no speech (Barbera & Rasmussen, 2007).

Behaviour Therapy based on Applied Behaviour Analysis (ABA) is a therapeutic method used by clinical psychologists. According to IAN (2016), intervention for autism spectrum disorder is based on two main approaches, the behavioural strategies and the developmental approaches. The most known treatment methods are based on ABA which is an approach that works on decreasing the negative behaviours and replacing it with the desired actions.

In contrast to the developmental approach, the key target is on developing skills through steps and stages. The most well-known are called Floortime based on Dr Stanley Greenspan's Developmental, Individual-Difference, Relationship-Based (DIR) Model (IAN, 2016). As IAN (2016) concludes the best treatments are now combined with both approaches in such a way as to gear the treatment to the best fit for the children.

2.3.2 Medical treatment including various supplements and special diets

As autism is a complex disorder, treating them involves multiple medical specialists. They include general practitioners, child specialists, neurological developmental child specialists, neurologists, psychiatrists to name a few.

Medications are given for various problems such as autism-related seizures, behavioural problems, sleep disorders, etc. Among the drugs, there are also certain supplements that autistic children are placed on. According to IAN (2016), there are certain prescriptive and drugs given to children with autistic spectrum disorder. These medicines are given not as a cure but to reduce or help to bring positive changes with the difficult, deviant issues in them (Swiss Medica, 2016).

Some medications target the brain such as antipsychotic drugs, antidepressants, stimulants, mood stabilisers, anticonvulsants and some that target the immunological system and the gastrointestinal tract. IAN (2016) states that there are also vitamins and supplements that are given such as vitamin C, Omega 3 fatty acids, vitamin B6 and magnesium therapy as part of the treatment regime.

There are also certain special diets that are used for children with autism. According to IAN (2016), though there is no real scientifically proven research, there are several different foods that are in used either alone or in combination with autistic children. Parents keep reporting significant changes in their autistic children behaviour when placed on such diets. These include IAN (2016, para 3):

- 1) Casein-free diet (casein is a protein found in milk; this diet eliminates milk and all by-products of milk)
- 2) Gluten-free diet (gluten is a protein found in many grains; this diet eliminates such grains)
- 3) Feingold diet (reduces additives and chemicals)
- 4) Specific Carbohydrate diet (removes specific carbohydrates including all grains, lactose and sucrose)
- 5) Yeast-free Diet (eliminates yeast and sugar)

As stated by IAN (2016) among the diets mentioned above, casein-free and gluten-free diets seem to have brought significant positive changes in autistic children.

New research has been ongoing in search of a cure for autism. Stem cell therapy is a relatively new medical approach which is showing improvement in autistic children such as improvement in their behaviour, increase attention span, improvement in verbal skills and development in many other developmental areas (Swiss Medica, 2016).

Thus, as can be seen above, children with autism need help from a multidisciplinary or a trans-disciplinary team consisting of paediatricians,

psychiatrists, speech and language therapists, clinical psychologists, occupational therapists, physical therapists, educational specialists, in the process of diagnosis and treatment (Dillon, 1995; Hamilton, 2000; Stone & DiGeronimo, 2006; Barbera & Rasmussen, 2007; Jepson & Johnson, 2007; Siegel, 2008; Feinstein, 2010).

2.4 Challenges Faced by Families of Children with Autism

The challenges that the caregivers face while raising children with autism can be related to several issues around this lifelong complex disorder (Rahman, 2005). The challenges can be either related to the severity of the children's condition, parental expectations for their child, societal awareness within the given society and the level of appropriate support services available for the children with autism and their families (Heiman and Burger, 2008). In addition to it, as autism is a life-long disability, the challenges faced by caregivers can be a never ending enduring process with varying issues to face, during the course of life, depending on other factors such as age and the gender of the child as well.

The challenges faced by the parents seem to start very early on. Although parents become aware of their children's developmental delays and deviances, getting a confirmed diagnosis is not easy, especially if the children are milder or when younger. Hence, the process of obtaining a diagnosis becomes an enduring challenging process for the families (Dillion, 1995; Jardine, 2013).

The next phase of the challenges starts off with getting a diagnosis of autism. For any parent, while expecting the child to be normal, receiving a diagnosis of a long-term disability surges emotions that create insecurities. Studies have shown sadness as

a prominent finding among mothers raising children with autism (Mann, 2013; Batman, 2011). In this process, the challenges they encounter can be a complicated process for the parents while grieving themselves but having to break the news to family and friends and as well looking for appropriate treatments for their child. The uncertainty of their children's future becomes an emotional process for most parents after receiving a diagnosis (Dillion, 1995). Change and frustrations, coupled with anxiety, also become part of the emotions of mothers raising children with autism (Jardine, 2008).

Finding appropriate treatment is the greatest challenges for many families raising children with autism (Hamilton, 2000; Jardine, 2008). Autism has been a complex disorder with no real cure and with relatively new specific treatments, getting through the process of getting appropriate treatments thus becomes a major challenge for the parents (Batman, 2011; Matenge, 2012). The challenges faced having the inability to get the necessary treatments throws the mothers into a pool of negative emotions such as unhappiness, anxiety, desperation and even isolation (Jardine, 2008; Batman, 2011). Such negative emotions also lead to having an adverse impact on family life and harmony (Matenge, 2012).

Parents having to raise an autistic child with multiple difficulties face certain adjustments issues within the regular family life. It can be working on finding extra time for the autistic child or giving sufficient time for other kids or family members as well as working around sibling jealousy (Hamilton, 2000; Siegal 2008). As a consequence, caregivers have to compromise and sacrifice certain personal issues as a means to work around and adjusting to the challenges (Jardine 2008; Batman 2011).

The other problems parents face are related to challenges they have to encounter within the community, mainly due to unawareness of the multiple deviances that the autistic children have, including communication and behavioural issues, especially in the absence of any obvious physical deformities. The most challenges arise from social stigma that goes with the behavioural issues that the children have (Mak & Kwok; 2010). Handling of stigma within smaller communities has been reported with its share of added difficulties and different set challenges within communities (Connolly, 2015).

Parents raising autistic children face varying challenges throughout their life as the challenges keep changing as the child grows older. Initially, what starts as searching for appropriate treatments, at an older age, are replaced by the challenges of finding appropriate schooling for the children. Hence, starting from birth, till they become adults, parents' challenges keep piling or changing as the journey moves on. The challenges highlighted above are further discussed under the section of 2.6 of this chapter.

2.5 Institutional and Societal Support Available for Families and Children with Autism

The process of raising autistic children is a complicated, and life-long ongoing treatment process with no definite cure. Irrespective of the form of therapy the children are on, from the treatments mentioned above, there is a significant role of some people involved in the caregiving process. Including the parents, there are other people involved such as extended family member, service providers, the state and even the

wider society. The main caregivers of autistic children need to be well supported for them to help their autistic children.

The ideal solution for parents raising children with autism would be a holistic support system; a support system that includes professionals with the knowledge and understanding of autism. It should be a system that can cater for early diagnosis and early intervention, and a system that is readily available for the parents and their families. It is important that the society is made aware of autism and the devastating effects of autism on the children and their families. At the same time, it is also important that the society can understand and empathise with the feelings of those affected and their families.

Stigma can be the cause of isolation for the children with autism and their families. Thus, socialisation becomes a key concern. According to Mak and Kwok (2010), public intervention should consider effects of stigma on autistic children and target on decreasing affiliate stigma.

Mak and Cheung (2008) also stress the importance of family-based intervention. The intervention should not only be for the parents but also for the other family members such as the siblings. Such programs should help the unaffected siblings understand autism and be able to meet the needs of their affected siblings. According to Hamilton (2010), the unaffected siblings' emotions can vary from anger, jealousy, lack of attention and even embarrassment. They may struggle with such feelings unless they are helped in a positive way. Hence, it is important that such issues are addressed to avoid it building into bitterness and resentment.

A study done by Heiman and Burger (2008) found that, in addition to family support within the family, there is a need for practical support programs that can empower the parents to help their children. The support for the family, in particular for the parents, in most cases the mother, needs to be adapted to their personal needs taking into consideration their individuals coping ability. This effort is necessary because each person's ability and the way they handle and cope with stress can be different. Interventions need to be aimed with such factors in mind for a progressive improvement of parents' happiness and well-being (Benson, 2010).

Lin et al., (2010) quoted several studies conducted in Taiwan (i.e., Hsieh & Shu, 2004; Shu, Hsieh & Li, 2001; Shu & Lung, 2005) that have indicated the benefits of structured support in reducing caregiver burden and enhance parent-child interactions. Heiman and Burger (2009) study also found that improving support can be a tool for increasing the competencies of parents. Family support thus needs to be recognised as an important part of children with autism.

Having said the above, although the benefit of social support for the families is positive, the acceptance and readiness, seeking and using such support can also vary within different cultural societies. Lin et al.,'s (2010) study that looked into the cultural differences in social support, coping strategies, family adaptations, and maternal well-being in Taiwan and the United States found differences within both groups and concluded that the differences might be related to the cultural norms and belief.

Therefore, it is highly relevant and important that when thinking of delivering social support and services for children with a disability such as autism, it is crucial

that the support is tailor-made for the receivers of the support considering individual differences as well incorporating cultural values of that given society.

2.6 A Journey: A Framework for Understanding Mothers Experience in Raising Children with Autism

In this section, the researcher conceptualises the mothers' experience of raising their children with autism with the help of a metaphor, 'a journey; a journey with a beginning, middle and a journey in progress. A journey embedded in multiple emotions and various challenges. A journey is accompanied by shock, disbelief, fear and uncertainty at the beginning. Realising that autism is a condition without a complete cure, even in the light of the all the new and successful treatments, makes this journey long-term, profound, and challenging. Thus, this complex and lifelong nature of autism have a long-term impact on the individual as well as their families.

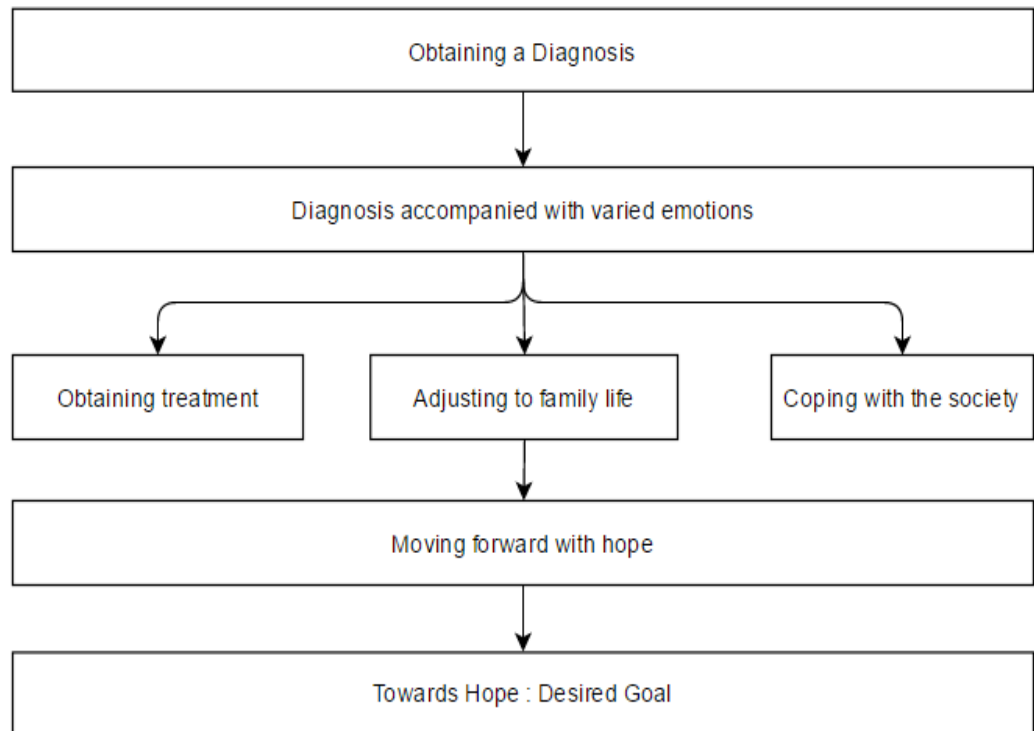
A study conducted by Jardine (2008) on the experience of parents raising children with autism have reported that parents in her study have shown to have through a journey with five distinct stages. They are making sense of symptoms, what diagnosis means, acceptance and adjustment, reflecting on progress and the future. A more recent study conducted by Mann (2013) on Jamaican mothers raising children with autism has also conceptualised the mother's experience as a journey. The findings of her study reported several themes that from the onset of birth, through the diagnosis and treatment stages on to the future. Hope seems to play a significant role in their journey as a means to a way forward; a journey through hope towards hope, to achieve what the mothers' desire for their autistic children.

As stated above, challenges around autism are multi-fold as it involves both emotional and situational hurdles that the mothers have to deal with. The issues that the mothers have to deal with can have its commonalities and differences which can vary depending on individual situation. The way how the mothers deal with certain issues can be dependent on personal and situational factors of those different mothers (Mak & Chueng, 2008). Stigma, for instance, is one such issue that the mothers may differ in the ability and the way the mothers deal with. A positive or an adverse reaction can be made worse or better depending on the environment they are living in.

The level of awareness in a given society can influence the way an issue is dealt with and also the impact can vary from situation to situation and person to person. For example, according to Corrigan and Watson (2002, in Mak & Kwok, 2010), the stigma that the parents and carers of children with autism have to face brings about negative emotions and behaviours. The impact can presumably depend on the support the mothers receive from their service providers and social services environment combined with the personal and emotional individual strengths of the given individual. Thus, getting an in-depth understanding of the life experiences of mothers of children with autism and considering their needs are critical and are important for the clinicians, the state and the society, to be able to meet the needs of the mothers of children with autism.

As mentioned above, the researcher will now portray the experience of the mothers raising their children with autism as a journey, a journey in progress with distinct but connected phases that the mothers go through as themes below.

Figure 2.1: A Journey in Progress



2.6.1 Obtaining a diagnosis

At the beginning of the journey of having to raise an autistic child can be the phase, the process that the mothers go through in the initial stages of trying to confirm the diagnosis. Sometimes this process happens to be an enduring process with several appointments from specialists and following a battery of tests. Dillion (1995) has highlighted the difficulties in getting a diagnosis for autism. According to Dillon “...it may take many frustrating months and even years, of this type of testing before the parents learn their child has the disorder autism” (p. 6).

Linn Hamilton talks in her book titled Facing Autism (2000) about her enduring journey and the several tests she had to go through with her son before her

son Ryan was diagnosed with autism. The previously mentioned study of Jardine (2013) also has reported that the parents who participated in her study also found their initial experience of the diagnosis process for an extended period. A study done by Tansley (2013) on the experience of parents of children with autism who attended residential school have reported the period of diagnosis as a frustrating period full of anxiety as they have to wait for the precise diagnosis after the assessments. According to some participants in Tansley's study, parents have found that with the initial meeting with doctors, there is a problem, but the doctors seem to be unable to give a clear answer until all the tests are done and confirmed, which a lengthy process is. Another study by Connolly (2015), on parents chosen from two counties of Ireland, whose children with autism spectrum disorder are starting primary school, talks about the lengthy diagnosis period and have said "*...the length of time spent waiting for the diagnosis which he felt was "absolutely crazy ... because it took so long for her to get a diagnosis and to get the help she needed"*" (Connolly, 2015:121).

According to some experts, the process of diagnosis can vary depending on the country and the person seeking the diagnosis. In the developing countries, the correct diagnosis may not even be possible due to lack of knowledge and the expertise. As Feinstein (2010) states in the chapter titled 'autism in developing nations', "*...many countries are only now coming to grips with understanding the disorder*" (p. 246). In some well-developed countries, the resources are such that diagnosis can be something which happens within a reasonable time, whereas, in some other countries the diagnosis can be so prolonged that parents may have to spend months and even years before their child gets diagnosed (Siklos & Kerns, 2007). Also, the length of time may be prolonged as it is critical to get a comprehensive assessment done which needs time as it also involves a process of appropriate guidance towards treatment. A

comprehensive assessment which requires a good in-depth look at the strengths and weaknesses of the child cannot be overlooked and shortened as such an assessment is the best possible tool that will guide towards a holistic treatment plan (Seigel, 2008).

2.6.2 Diagnosis accompanied by varied emotions

The diagnosis of their children having autism, a life-long disability unleashes a lot of painful emotions for the mothers. According to Williams (2001), like all other life-long disabilities, the initial shock of discovering that one's child has autism can be devastating for any parent. The range of emotions can be varied among mothers ranging from shock, denial, disbelief, sadness, fear and uncertainty at one end and a sense of relief at the other. As Dillon (1995) states, finding out that your child possibly has autism, a lifelong disability, can have a devastating effect on the sense of loss to future uncertainties to the fundamental inability to even acknowledge and accept something so unexpected, and in some cases unheard of.

For mothers, the sudden shock of receiving such a diagnosis can initially lead to a sense of denial. As Williams (2001), a psychologist and a parent of a child with a disability, states that denial is a useful defence mechanism at the time of unexpected difficult situation. According to Williams, when people are faced with unexpected difficult situations such as a disability, they go into denial and buy some time in trying to digest the shock little by little which then becomes more bearable. Williams further explains that adjusting is a process and takes time because no parents are pre-prepared for having a child with a disability.

The Mann (2013) study on Jamaican mothers has reported sadness as the most prominent emotion among the mothers after receiving the autism diagnosis of their

children. The Batman (2011) study on the maternal subjectivity of raising children with autism has found that profound sadness with getting their children's autism diagnosis. Batman further reported that some mothers who initially had a sense of relief after the receiving the diagnosis were later changed into sadness.

Another recent study done on South African mothers raising autistic children by Matenge (2012) have reported very similar findings to that of what was found by some mothers of Batman study. The initial sense of relief that the mothers experienced after initially hearing the autism diagnosis turned into grief and sadness. As Matenge explained the reason for this seemed to be mothers' realisation of the life-long nature of autism.

In the study by Tansley (2013) on the experience of parents of children with autism, some parents have reported the final diagnosis as a feeling of loss as they were hopeful to have a less profound diagnosis. In the study done by Connolly (2015) on the experience of parents whose children with autism spectrum disorder starting primary school, one of the mothers has reported a sense of 'sinking feeling' and 'slipping away' after hearing her daughter's diagnosis of autism.

In the midst of the shock of hearing a label such as autism for their children, parents also seem to start having fear and uncertainty as adjusting to a life with a child with a life-long disability. For these parents, it is not just a one off issue, but a lifetime commitment. According to Dillion (1995), one of the major concerns that roots from having realised that their child has autism are the fear of uncertainty about the future of their child. According to Dillion, parents' mind gets bombarded with questions starting from how to handle the present to uncertainties of their future. Questions that

parents ask can be as broad as ‘Will my child get better or worse? What about sexuality? Will this become another major problem? Will they be able to be gainfully employed as adults? Will they ever be able to live independently? And if not, will the parents be able to manage them as adults? What about after the parents die; who will care for them?’ (Dillon, 1995:37). While such questions are running through one’s mind, managing the fear and adjusting to the diagnosis and what follows can take months if not for years. The fear and uncertainties also can never be ending because as different stages will bring a new set of emotions as the process prolongs.

The diagnosis is believed to be important as it becomes the key to the door of services (Seigel, 2008). Hence, it’s critical that the mothers can accept the diagnosis as soon as possible in order to move on to the next phase. But as can be seen above, acceptance is not an easy thing when it comes to accepting one’s presumed normal children having a life-long disability. Hence, parents tend to go through a process of re-evaluating and re-confirming the diagnosis. Generally, in these early stages, when parents are going through the battery of tests for diagnosis, they may be still going through the process of denial before being able to accept the diagnosis of autism. For some families, getting the diagnosis can become a relief as they now have a name for their child’s problem, and they can now start working on it. On the other hand, others may not so readily be able to accept the diagnosis (Seigel, 2008).

The journey of parents continues to go on to innumerable lengths in the hope of finding an appropriate treatment for their children. During the initial process, parents tend to go in search for answers, finding a treatment, a cure. The desire of the mothers’ determination to succeed in finding help for their children can be immense. According to a mother of an autistic child, Hamilton in her book on Facing Autism

(2000), she can relate to and understand the determination and the great lengths mothers would go to, she believes 'it will be your determination that will drive you to seek answers and help for what your child needs most' (Hamilton, 2000:199).

2.6.3 Obtaining treatment for the child

A complete cure for autism is unknown (IAN, 2016). But, early diagnosis and intervention are crucial for the children with autism and their families (Heimen & Burger, 2009). As mentioned above, under the heading on treatments available for autism, there are extensive medical as well as therapeutic treatments available for children with autism. Though there are many approaches to treatment; there seems to be no one treatment that works best for any given child. Also, achieving the desired success with treatment depend on the children's severity and the age the treatments are started as understandably early intervention is a means of achieving success. But obtaining treatment seems to be one of the hardest things mothers' face, especially along with the emotions after hearing the diagnosis. Mothers seem not to have time for even mourning for their children's condition as they realise the importance of treatment.

Several books written by mothers and parents, on stories of raising their autistic children, have reported their difficulties of obtaining the necessary treatment for their children. The book written by Dillion (1995) based on six parents and their journeys of raising children with autism have reported that obtaining adequate treatment has been an area that parents found difficult. Another book written by Lynn Hamilton (2000), based on her journey of raising her son with autism, have also stated that being on the waiting list is an unknown length of time hence its best to get on the waitlist as

early as possible; as she says “...it may take months or even years to become eligible” (Hamilton, 2000:70).

Recent studies done on experiences of mothers and parents raising children with autism have also reported similar findings. Most of these recent studies done on understanding the experiences of parents raising children with autism have reported several negative emotions associated due to the difficulties and challenges of obtaining treatment for their children. The study done by Jardine (2008) on the meaning of parents raising their autistic children have reported several difficulties and challenges while obtaining treatment and adjusting to life which has made the mothers unhappy, anxious and isolated. The process of adjusting to the child’s needs working on areas such as behavioural issues in their children have not been easy on the parents especially with lack of social support and awareness.

The study conducted by Batman (2011) on the experience of mothers raising children with autism has also reported similar results as above. According to Batman, “...Jennifer’s emotional experience parallels that of most interviewees in that each barrier in the treatment and service-seeking journey invoked despondency, isolation and desperation” (p. 78). The frustrations of the mothers that result from the challenges of obtaining the desired treatment for their autistic children seems to not only affect the mothers alone, but as a consequence, it also appears to be transferred negatively on to the other significant members of the family including on to their autistic children.

A more recent study done by Matenge (2012) in Cape Town on lived experience of mothers raising children with autism have reported the frustrations in

the process of obtaining services have resulted in some mothers to have negative emotions even towards their families, including their autistic children.

2.6.4 Adjusting to family life

Parents with autistic children face with difficulties and challenges within their family which cannot be of a positive nature. Such difficulties can be the result of the deviant behaviours in their autistic children. The challenges that accompany with disabilities have a significant impact on the whole family (Williams, 2001). Likewise having other kids has significant consequences for the families with autistic children because ‘autistic behaviours do not happen in a vacuum’, but rather affects the whole family (Dillon, 1995:22). Parents, as well as the siblings, can also be affected by having a brother or a sister with autism in the family. According to Hamilton (2000), “...siblings are often jealous of the extra attention given to special needs children, especially if they are undergoing an intensive program” (p. 265). Some kids may find themselves unable to cope with their autistic sibling especially if they are younger themselves. Hence, siblings may show some form of negative behaviour in the process of getting attention for themselves from their parents who are too busy with their autistic child (Siegel, 2008).

Parents may also find themselves in a tug-of-war with having to balance their time and attention between their children or even between their partners in a balanced way. Heiman and Burger (2008) studies have indicated that families with children diagnosed with Asperger have a different set of daily life routines they need to work on, unlike having a child without a disability. As a result, mothers with disability children can have significantly higher level of strain on their family life.

Mothers may be in more than one way affected by having and raising children with autism. Sometimes it makes them isolated from the social world due to the difficult challenges that go along with autism. According to Woodgate et al., (2008), the isolation of parents was felt not just outside their homes, but they also have a similar feeling even within their family. Mothers were unable to cope with their autistic children and continue to be part of their regular family events. Heiman and Burger (2008 in Little, 2002) stated that mothers of such children also experience significantly higher level of stress and also perceive stress of other family members, more than the fathers of such children.

Another paramount issue of concern within the family can be the relationship of parents with each other and on their marriage. According to Dillion (1995), raising a child with autism can strain the marital relationship. The intimacy between couples can be lowered due to several factors such as maternal stress, lack of time accompanied by physical tiredness due to coping and dealing with the autistic children behaviours such as tantrums, running around with extra daily activities such as treatments, and on top of it, balancing life with other non-autistic children. Living with Autism in Malaysia, Policy IDEAS 2015, also highlights strain on families raising children with autism often resulting strain on marriages (Lim, 2015).

Recent studies conducted on mothers and parents' experiences of raising children have also reported various challenges in the process of adjusting to the family when faced with having to raise their autistic children. As mentioned above, it seems to be resulting either due to the difficulties the child has or due to time constraints caused by additional activities that come along with the treatments. According to the

study conducted by Jardine (2008), the parents having to challenge themselves consciously to try to keep with the family routines to balance it for the whole family.

Another significant challenge mothers are forced to face is their relationship with their husbands. The Batman (2011) study reported such a finding saying that *“...for all participants, the responsibilities of carrying out the business of autism significantly impacted the family dynamic and placed considerable stress on participants’ relationships with their partners”* (p. 84). Here what Batman means by ‘carrying out the business of autism’ is the extra things that came along with having to as arranging appointments, getting there on time, being the advocate for their children, etc.

2.6.5 Coping with the Society

Societal stigma is another challenging and a significant area of concern for mothers of autistic children. Stigma is also not something that affects just the affected individual with autism. Stigma also affects significant others of the individual such as parents, family members, friends and even the service providers (Mak & Cheung, 2008).

The adverse effects of stigma can have negative psychological implications such as reduced self-esteem, social disadvantages and even may delay seeking appropriate health care that is so important and crucial (Mak & Cheung, 2008). There are different types of stigmas that need to be addressed at different levels. They come under self-stigma, public stigma and affiliate stigma. Each of these various types of stigmas can lead from one type on to another and can complicate the process and can have enormous implications for the mothers and the children with autism as well. A study done by Mak and Kwok (2010) on internalisation of a stigma of parents of

children with autism in Hong Kong reported that parents stigmatised by blame and expectations from public, in turn, internalised the stigma as affiliate stigma.

When thinking of issues around stigma, it is also highly important to embrace the societal and cultural differences within a given society and as well understand the effects and level and type of stigma that affects the individual and the significant others for the purpose of appropriate intervention (Mak & Cheung, 2008). According to Mak and Kwok (2010), courtesy stigma is high in certain societies due to how they value social behaviours. A condition such as autism with its nature of repetitive and deviant behaviours, it tends to be tough for mothers especially in social situations when she and the children are being watched on. Just like with other disabilities, such as intellectual and developmental disabilities, that are not physically evident, when the society blames the mothers, then, some mothers start blaming themselves for the inability to control their children's behaviour.

According to Mak and Kwok's (2010) study, an in-depth look is vital because, for example, support from friends and significant others were found to have helped in reducing affiliate stigma, but, on the other hand, family support does not help much in the reduction of affiliate stigma. The possible reason was thought to be that other family members themselves were stigmatised as well as the parents themselves. The Mak and Kwok's (2010) study also suggested that public education and exposure to autism of the public as a necessary ingredient and is critical in the intervention process. Due to this intertwining nature of different types of stigmas, it is important to have an in-depth look at all areas of the home, society, culture, etc., if we were to help and support parents and children with autism successfully.

More recent studies, such as the study conducted by Connolly (2015) on parents chosen from two counties of Ireland whose children with autism spectrum disorder starting primary school, reported stigma associated with their autistic children and talks about how others perceived autism. According to Connolly, some mothers in her study were reluctant to let anyone beyond family and very close friends know their children have autism. One mother of a child with high-functioning autism has deliberately kept the diagnosis undisclosed in fear of rejection and exclusion of her child from activities such as play dates.

Sometimes, this particular mother has also avoided enrolling her child in a special class once again as reported out of fear of stigmatisation. From this study, it appears that even today, small communities are faced with stigma due to the nature of small communities. In Connolly's view, the mother, "*...Hannah mentions the small town, and I had the sense of her implicitly talking about 'small town mentality' where everyone watches everyone else, and your history is always remembered. Hannah did not want stigma to follow James and perhaps, herself, throughout his life*" (Connolly, 2015:130).

2.7 Role of Hope in the Journey

Hope plays a significant role for the mothers of children with autism in their journey. Hope is something that any individual clings on to when they are faced with difficulties of life. The need for faith becomes stronger and important when people are confronted with life-long challenges such as raising children with a disability such as autism.

According to the Oxford Online Dictionary (2016), hope is an expectation of the fulfilment of one's wish or desire; the 'grounds for believing that something good may happen'. It is a feeling of trust. In this case, it is a reasonable belief of finding a cure or treatment for their children. The meaning of hope for one mother can be different from another. For some mothers, hope may be a person with the knowledge and the ways to help them with their children, and for another, it may mean finding a cure in the form of medicine or specific treatment for their children with autism.

Hamilton (2000), as a parent of an autistic child, says "*I hope that someday someone will find a cure for autism that will free all children of its devastating effects*" (p. 306). Sometimes for people who have not experienced such a difficult situation in life, clinging to hope, wishing and expecting, can be viewed as unrealistic. According to Hamilton, hope plays an important role for parents of children with autism as a means of holding on through their journey until they reach the destination. At times, it can also act as the primary anchor or a shield for survival until the person can start dealing and coping with difficult issues of helping their child. In essence, hope acts as a motivator towards a better future (Hamilton, 2000).

Even for those parents of children who are severely affected, hope is what gives them happiness and drives them towards the future. As another parent, Susan, mother of a child who is severely affected by autism has said: "*...we never, ever stop hoping that one day Franke will be able to speak his own name*" (Hamilton, 2000:310). This holds true for many parents of children with autism. As Hamilton stated in her book, *Facing Autism: Giving Parents Reason for Hope and Guidance for Help* (2000), "*...if you have a specific hope in your heart for your child, don't throw it away. If you choose to give up your hope because others tell you it isn't possible, you will be defeated*

before you begin. We each must follow the hopes and dreams that we have been given”
(2000, p. 315).

2.8 Conclusion

The review of related literature on autism and parents raising children with autism has made it abundantly clear that there are many significant issues that need to be addressed around this complex condition, a life-long disability with a never-ending journey of treatments and challenges. Autism, with its high prevalence, has significant implications and is an area of concern for all countries, especially for developing countries with limited resources. Autism does not just affect the child alone who has autism, but it affects their siblings and their families as well. Mothers raising children with autism can have many possible challenges that they will encounter in their journey of raising autistic children. Many countries, NGOs and individuals, have researched and is still continuing to research in finding answers for the high prevalence of autism. Research is ongoing in finding ways to reduce the impact through types of treatments and support programs for the parents, children and their families. Researchers are continuing to look for a possible cure for autism, a dream that mothers and parents of autistic children hope to be true. In general, hope plays a vital role for the mothers of children with autism in their never-ending journey.

CHAPTER 3 : METHODOLOGY

3.1 Introduction

The aim of this chapter is to present the research design, theoretical underpinning of the research methodology and the role of reflexivity in this investigation. Then it is followed by the research context and the key aspects of the data collection. The chapter will be concluded with the discussion on the data analysis process and the ethical considerations.

3.2 Research Design

The research methodology chosen is based on the fact that the primary concern of the study is to explore into the life histories and lived experiences of Maldivian mothers raising children with autism, and to get an in-depth understanding of their journey as they have lived and the meaning, they ascribe to it. Qualitative research is believed to have the ability to explore people's experience of life in our social world and allow us to use methods that go into a deeper understanding of the complexities of peoples' life experiences (Berg, 2007; Mason, 2002; Brockington & Sullivan, 2003). Mason (2002) stated that:

“...through qualitative research we can explore a wide array of dimensions of the social world, including the texture and weave of everyday life, the understandings, experiences and imaginings of our research participants, the way that social processes, institutions, discourse or relationships work, and the significance of the meanings that they generate.”

(pp.1).

The issues around raising children with a long-term disability such as autism as well as the experiences of the mothers who go through such a process can be closely related to the individuals' cultural and societal context. According to Barbosa et al., (2008), the sensitiveness of such issues is surrounded by disappointments and hopelessness for the parents of children with the disability. According to Laws, Harper and Marcus (2003), choosing an appropriate method in research is the key when studying difficult issues and have to consider cultural diversity of different cultures in the ability to discuss sensitive issues. Hence, the significance of the socio-cultural milieu of the context of the study is also considered while selecting the method keeping in mind that the Maldives is a close-knit community where people know each other at some level or other. The present research has taken the factors as mentioned earlier in consideration and has chosen a qualitative method that is believed to be an approach that will fulfil the objectives of this study.

3.3 Interpretative Phenomenological Analysis

The theoretical perspective or the theoretical lens in which the research is shaped through considering the uniqueness of individuals and their existence in their social world. In the context of this study, it is by acknowledging the mothers' experiences having faced with a difficult issue in life, such as raising their children with a life-long disability such as autism.

The most relevant theory is the theory of existentialism. The existential theory is based on how a person derives the meaning of their existence in the world. According to Clay (2013), “...*existential approach centres on the belief that inner conflict within an individual stems from that individual's confrontation with the givens*

of existence” (p.4). Hence, it is about how an individual embrace and interprets their personal life experiences from their existence to the world they live in. According to Engler (1991), “... *existential anxiety is a critical part of life. As individuals become more aware of the choices available to them, they are also more aware of the consequences of those choices.*” (Cited in Clay, 2013, p. 6).

The qualitative design selected is an Interpretative Phenomenological Analysis (IPA). “*IPA concerns with the in-depth exploration of participants’ lived experiences and how they are making sense of the experiences*” (Smith & Eatough, 2006, p. 327). According to Smith and Osborn (2008), in IPA “...*the aim is to explore, flexibly and in detail, an area of concern*” (p. 55).

IPA derives its roots from phenomenology. Phenomenology as a philosophy was initially developed by Husserl and later has been extended by other philosophers such as Heidegger. According to Husserl, the ‘essence’ of a phenomenon can be understood through the person’s lived experience (Clarke, 2009). Though these philosophies have a similarity in the basis (as Heideggerian was an extension of Husserl’s phenomenological philosophy), they both differ in terms of its aim and how it is used. The Husserlian phenomenology is descriptive in nature thus describe the participant’s lived experience. Whereas, Heideggerian being interpretive in nature further emphasise on analysing the research material thus interprets the participant's experience in trying to understand what it has meant to them (Clarke, 2009).

In addition to Husserl and Heideggerian, IPA has theoretical underpinnings of two other philosophers, Merleau-Ponty and Sartre both of which have links to a person’s existence in this world and how each’s presence means to them. Smith et al.

(2009) state “...for qualitative researchers in general, and IPA researchers in particular, Merleau-Ponty’s view that the body shapes the fundamental character of our knowing about the world, is critical” (p.19). According to Smith et al., (2009) Merleau-Ponty describes “...the embodied nature of our relationship to that world and how that lead to the primacy of our individual situated perspective on the world’, and continues to say that ‘Merleau-Ponty suggest that as humans we see ourselves as different from everything else in this world” (p. 18).

When we research into individuals lived experiences of lives events and the meaning, they have, to the complexities of their lives can only be understood from their personal existence. According to Smith et al., (2009):

“...Sartre emphasised that we are caught up in the projects in the world. While we have self-consciousness and seek after meaning, this is an action-oriented, meaning-making, self-consciousness which engages in the world we inhabit. Sartre stresses the developmental, processual aspect of human being. His famous expression ‘existence comes before essence’ that we are always becoming ourselves, and that the self is not a pre-existing unity to be discovered, but rather is an ongoing project to be unfurled.”

(p. 19).

IPA also embraces the fact that while researching into people’s lives the researcher is in an active role in which the researcher’s pre-perceptions are integral to the research process. The pre-conceptions are deemed to be important in the process of understanding and interpreting the participants’ experience. Therefore, Smith and Osborn (2008) states that IPA is a double hermeneutic process in which “...the participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world” (p. 53). IPA, therefore, is in harmony with its phenomenological roots whereby taking the participants side from their standpoint (Smith & Osborn, 2008).

IPA also had been found to be a methodology that is relevant to research in psychology, health and moreover is found to be an appropriate method in therapeutic areas such as occupational therapy (Fade, 2004; Smith & Eatough, 2006; Smith & Osborn, 2008; Clarke, 2009). Among example questions of what an IPA study is suitable for is to answer a question such as “how do parents manage the challenges of living with an autistic child?” (Smith & Eatough, 2006, p. 327). It is a person-centred approach, thus, is useful in understanding the experiences of clients and caregivers and “...therapists can use findings to develop interventions and services that directly meet the clients, carers and staff needs” (Clarke, 2009, p.1). In short, IPA is very relevant to this study; that is to get an in-depth understanding of the lived experiences of Maldivian mothers raising children with autism.

3.3.1 Reflexivity within the research

In conducting IPA research, reflexivity is one aspect that needs to be well thought of as a researcher from the beginning to the end of the study. According to Parker (2005), “...reflexivity is a way of working with subjectivity in such a way that we are able to break out of the self-referential circle” (p. 27). Clancy (2013) states reflexivity as the clear awareness of self about the research because we as researchers are not neutral data collecting machines; hence reflexivity involves our willingness and ability as scientists to acknowledge our possible subjective influential position on the research process. According to Fade (2004), “...reflexivity is viewed as an optional tool, enabling the researcher to acknowledge his or her interpretative role formally, rather than as an essential technique for removing bias” (p. 648). In IPA research, the researcher’s belief is necessary in the interpretation of the participants lived experience, in other words, IPA embrace the researcher as a valuable analytical tool (Smith et al., 1999).

Considering the above, the researcher had to bring into surface some pre-conceptions the researcher held about Maldivian mothers' experience of raising autistic children as the researcher began this study. To do this, firstly the researcher believed that it is important that she reflects on her stance as a Maldivian mother who has gone through a process of raising her child, younger siblings, nieces and nephews from the same community. Secondly, the researcher also found it important to reflect on some pre-conceptions that the researcher hold which has been conceptualised over 25 years of experience as a clinician in the field of speech pathology and therapy.

For the purpose of surfacing some of the researcher's preconceptions, the researcher has been sharing her pre-existing and theoretical concerns and hunches at different points of the research process with her research supervisor, and also a colleague from the same socio-cultural context, who is one among the specialists from the multidisciplinary team which the researcher belongs to. The investigator's subjective preconceptions which in some ways significantly related to the topic of research are as follows:

- 1) The researcher believes parents, mothers and fathers play equal but complimentary roles in raising their children. Meaning to say they are equally responsible but their respective roles are different in raising their children. This belief comes from her experience of how she has been raised in the society as well as what the researcher has seen in many parts of the world during her academic and professional life.
- 2) The researcher also believes that predominantly mothers take on the role of the main caregiver especially with children with developmental or life-long disabilities. This belief seems to be ingrained in her through years of experience as a clinician.

- 3) For some unexplainable reason the researcher also intuitively believe that mothers, in general, are in some ways more sensitive to children's developmental and behavioural problems in their children. Mothers also appear to be better in dealing with such issues especially when children are young. This idea has partly come through the researcher's clinical experience of working with mothers of children with disabilities.
- 4) Strangely enough, the researcher also finds for some reason that mothers seem to love their children unconditionally from the moment of or even before the birth of their children. As a result of this unconditional love, the researcher also believes that mothers have a willingness to sacrifice anything, just anything for their children especially children with lifelong disabilities. The findings of this research have reaffirmed the researcher's belief about mothers but at the same time have enlightened the researcher about the father's love and their level and willingness to make sacrifices for their autistic children.
- 5) The researcher was also under a pre-conception that mothers, when their children are diagnosed with autism, goes into a deep shock, and it would be a long emotional period for them. But the findings of this research have compelled the researcher to completely re-conceptualise her pre-conception.
- 6) The researcher also has a strong belief that coming from the socio-cultural context, a hundred percent Sunni Muslim population, spirituality, faith in Allah (God), will play a sensitive and an intense role in the mothers' acceptance of their children with a life-long disability, the level of sacrifices they are willing to make, the strength and the ability in facing the innumerable challenges of raising their autistic children.

- 7) Last but not the least the researcher also believed that what the mothers are always looking for is a complete cure for their children's condition, which has also been somewhat altered after the findings of the study.

3.4 Research Context

Maldives is an island nation located in the north-central Indian Ocean which consists of about 1,200 islands of which 200 islands are inhabited. Maldives is a developing country, and its gross national product (GNP) is still among the lowest among the developing countries in the world. Maldives has gone through a change in its political system and in 2008 the country had its first democratically elected president (Encyclopaedia Britannica, 2016).

National Bureau of Statistics, Maldives (2015), based on Census 2014 reports that the resident population of Maldivians is 338,434, and the foreign population is 63,637. Out of over 100,000 people live in the capital Male', which is a land space of just 5 km in circumference. Maldives is a hundred percent Sunni Muslim community belonging to the school of Shafii. Sunni Muslim's attempts to cultivate practical applications of revelations of Prophet Muhammed (S.A.W) (Oxford, 2017).

Over the past few years, there has been a shift in the infrastructure where the previously centralised country is going through a decentralisation process. Though such changes are taking place still the focus point for health-related speciality services are in the capital of Maldives, Male'. The country is geographically divided into 19 Atolls and politically divided into 20 Atolls. There are six regional hospitals in

different areas in the country with the main focus on primary health care. The capital Male' is almost at the centre of the island chain.

Maldives national economic situation have gone through a vulnerable period following the December 2004 Tsunami which have devastated the country's economy to as low as 4.6 percent but this conditioned has got better the years through the tourism industry (Commonwealth, 2017). The economic development of the country has been broadly favourable for the three decades, a success story, though with of a fiscal deficit is showing to be a threat (World Bank, 2017). According to World Bank (2017) between 1990 and 2015 there has been an increase in GNI per capita by over 200 percent. The GDP- real growth rate was estimated at 3% with a GDP per capita (PPP) USD 15, 300 in year 2016 (CIA World Factbook, 2017).

According to Index Mundi, Maldives has become a middle-income country over the past few decades with the help of tourism and fishing industries but they too have indicated that the country is still have to cope with growing fiscal deficit. According to Index Mundi, the overall unemployment is 11.6% of which 25.4 falls on young adults between ages 15-24 (CIA World Factbook, 2017). Under the Country Partnership Framework (FY2016 - 2019) the World Bank Group support is aiming to improve the employment opportunities of Maldivians.

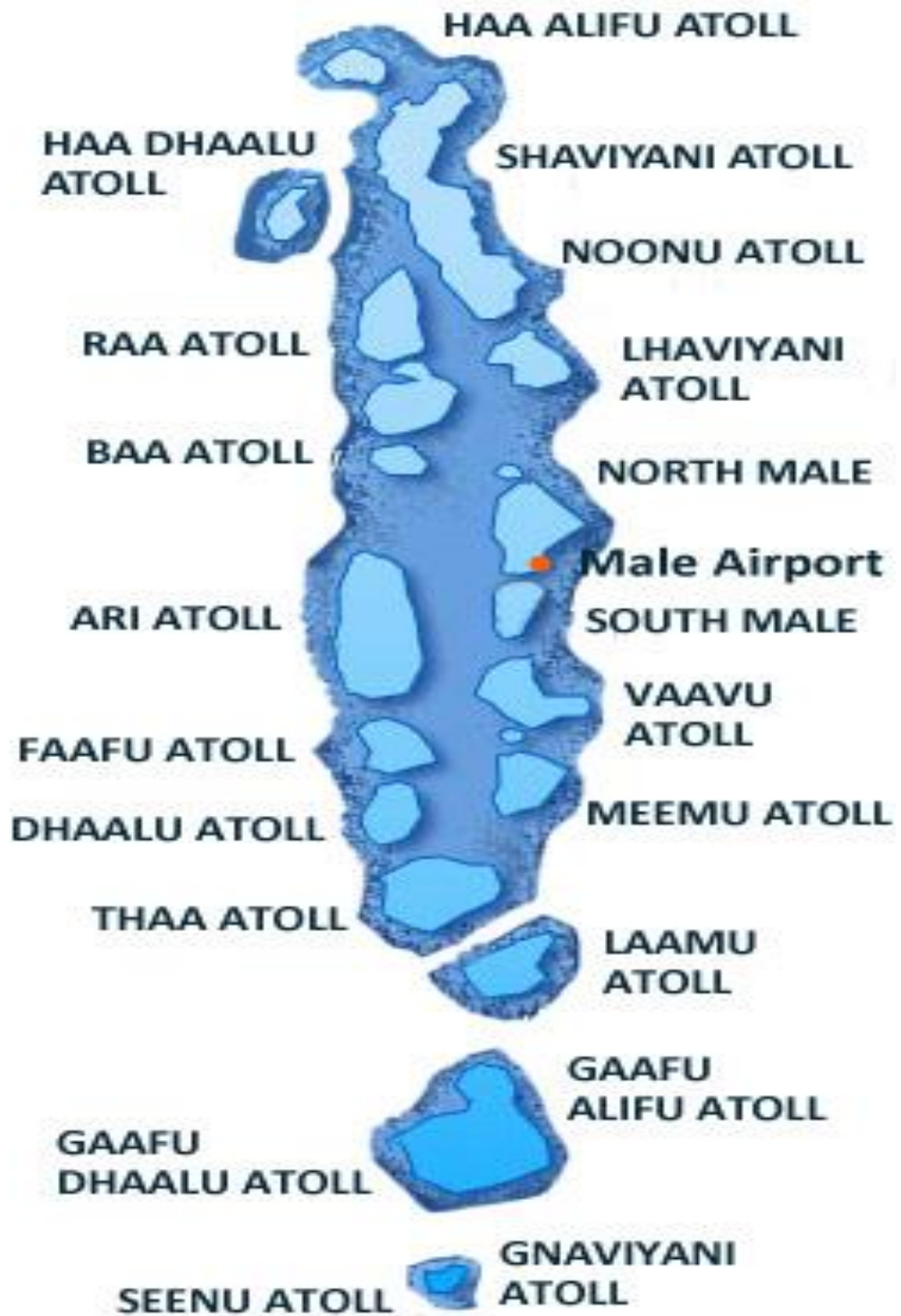


Figure 3.1: Map of the Maldives showing the twenty politically divided Atolls (Reefscapers, 2000-2017)

The first baseline assessment survey on mental health conducted in Maldives in 2006 by World Health Organization (WHO) reports that mental health facilities are only available in Male', the capital. The disability report of April 2010 titled 'Activities Addressing Rights of Persons with Disabilities: A Baseline Assessment', conducted by the Human Rights Commission of the Maldives, reveals that there are about 24,000 physically challenged people in the Maldives. This report had several recommendations regarding people with disabilities. They include early identification and intervention initiative for disability as well as raising societal awareness and working towards protecting the rights and dignity of people with disabilities (HRCM & UNDP, 2010).

Soon after the baseline assessment, Maldives Disability Act was passed in 2010 as well Maldives established a Disability Council and a Disability Register. Even though the government's target is to cater for the disabled with equality and harmony, the government face many challenges due to factors such as its unique geography with the population highly distributed in different islands within the Atolls. Hence, Maldives have reached out for international support and assistant in the process of achievng their goal (Maldives Mission, 2010-2016).

According to the Department of National Planning Statistics Division (DNPSD) Maldives, in the Incheon Strategy Indicators - Goal 8: Improve the Reliability and Compatibility of Disability Data, the target is to achieve a reliable disability statistics of the country by mid-2017. A set of statistics which will be credible and comparable to the international disability statistics of persons with disabilities. Though differential statics is not officially available, the researcher being one among the clinicians working with individuals with disabilities over the past two

decades, has seen an increase in autism and related disorders within the country over the last decade. This phenomenon of increase in number of children with autism in the Maldives, is very much in line with the statistics of a sudden increase of autism in the world (Hamilton 2000; Baird et al. 2006; Feinstein, 2010).

The family life in the Maldives has features that portray family life of a small community nation. Family network is such that many families still live with their extended family members. Even if not living with the extended family, parents of young children do depend on their elders such as grandparents, aunts or in-laws in daily caregiving, if both parents work, which is a common practice in Maldives. However, the norm of family life in Maldives is changing from living with extended family, to a more nuclear model of living. This practice has its fair share of the positives and the negatives, especially while raising an autistic child with many developmental deviances. In addition, more women are joining the workforce which consists of over forty hours per week. There is also an increase of employing foreign nannies within the nuclear homes.

Social care system in the Maldives is also going through a rapid transition with the introduction of a new health insurance scheme. Although there are limited professionals working in the area of disabilities, the national health system only pays for treatments available within the state hospitals and medical centres. Hence, for some families consulting a specialist in the private sector becomes an expensive process, which not all can readily afford. It becomes an additional hardship for parents in getting the appropriate treatment for their autistic children.

3.5 Population of the Study

Although there are some regional hospitals in the country, the speciality services such as treatment for children with autism are limited to Male'. Families with children with any disability from the other parts of the country come to Male', seeking professional help. Hence, more than two third of them either re-locate to Male' for good or for a specified period while obtaining treatment for their children with autism. Sometimes this happens at the expense of difficult living arrangements of intense proximity, a condition faced by most people living in the capital. Furthermore, they may even go to other neighbouring countries such as India, Sri Lanka, Singapore or Malaysia for a given period in search of treatment, cure, or to seek a second opinion and further guidance, at least once or twice during the first few years of their journey.

The actual stakeholders, the people who have lived their lives and have experienced the journey of raising children with autism, have been considered as the participants of this research study. The population from which the participants were drawn are from the mothers whom the researcher (a speech pathologist and therapist based in Male') have come in contact with, in a professional setting. Speech and language therapy happens to be among the few speciality services related to autism that is consistently available within the country, from 1988 till to this date. As IPA requires a sample that is as homogeneous as possible (Smith & Osborn, 2008), the participants selected from the population, as mentioned earlier, will fit into the pre-defined criteria that are detailed below under 'participant selection'.

3.6 Participant Selection

In the participant selection process, few important considerations are taken into account. In qualitative research, it is not easy to identify or get access to the appropriate subjects needed for the research. It is also not always possible to obtain participants that fit correctly into the frame of the research question (David & Sutton, 2004). Thus, identifying the subjects was part of the process.

Purposive sampling is considered to be the most ideal in qualitative research, a sample, which is about selecting the most appropriate and related to the area being examined (Laws et al., 2003). And, IPA is a research methodology that requires a sample that is as homogeneous as possible (Smith & Osborn, 2008). Therefore, for this reason, a homogenous purposive sampling is chosen for the research.

As the researcher belongs to the group of few professionals among the specialists treating children with autism in the Maldives, the researcher had contact and a working relationship with many mothers of children with autism in the Maldives. Thus, the mothers who were chosen as participants of the research were mothers who have at some point or other have come into contact with the researcher through the treatment process in a professional setting.

Out of the six participants, three mothers were those with the oldest children that the researcher has been working with. The other three were participants who had much younger children. The participants (Maldivian mothers) are drawn in the light that they are the people who have experienced the journey of caring for a child with autism.

In order to keep the participants as homogenous as possible the following selection criteria were used:

- 1) A mother of a child who at some point in their life been identified, labelled or diagnosed by a medical or paramedical practitioner as a child falling within autism spectrum disorder.
- 2) The period of such a diagnosis and the time of participating in the research are at least three years or more i.e. at least have experienced few years of raising their autistic child.

The number of participants selected for the study has followed the guideline of participant selection for IPA (Smith & Osborn, 2008; Smith et al., 2009). In IPA, if desired, the study can be conducted with a larger sample, if the aim is generalising the findings. But according to Smith et al., (2009), the real essence of an IPA is not so much to do with numbers but more with the rich, in-depth detail derived from the interview, which is believed to be possible with using smaller numbers. Smith et al., (2009) have suggested a sample size of six is an adequate number for a good IPA study, and three can be seen as an ideal number for first-time researchers. Smith and Osborn (2008) states that “...*this allows sufficient engagement with each case but allows a detailed examination of similarity and difference, convergence and divergence*” (p. 57).

Hence, considering the above factors, as the aim of this research is to get an in-depth understanding of the participants’ journey with also sufficient rigour, a smaller manageable sample of six Maldivian mothers raising children with autism, had been chosen.

To honour the participants' request for anonymity, the researcher is only able to give a brief and general description of the six participants. Out of the six mothers, three mothers had over ten years of experience in raising their autistic children; their children are between ages ten to twenty years old. These three participants were chosen as the more engaging cases as they have had the longest experience with their autistic children. Whereas the other three mothers have an average of three to four years of experience after their children were diagnosed; their children's age is on average five years. All six mothers are from the Maldives, but they come from different socio-economic and educational backgrounds. Table 3.1 provides some significant information about the participants. In addition to the table 3.1 an ecomap for each participant is provided (Figure 3.2).

Table 3.1: Some significant information about the participants

Name	Participant's Age	Child's Age	Educational Status	Financial Status
Xena	35 to 45	20	O'level	High
Yara	35 to 45	15	Diploma	Average
Zafa	35 to 45	13	O'level	Below Average
Aena	25 to 35	6	O'level	Semi High
Bera	25 to 35	5	O'level	Average
Cefa	25 to 35	5	Diploma	Below Average

The ecomaps provide some important information about the participant's relationship to significant others. The eco-map shows the strength of the connections through the number of lines which connect the main circle in the middle to the outer circles. The straight bold lines of the ecomap represent a positive strong connections

and dotted lines represent weak vulnerable connections. A squiggly line represents stressful and adverse connections.

Figure 3.2 shows Yara's ecomap showing positive strong connections with husband, SPLT, child, and other children. Yara also has weak vulnerable connection with friends while stressful and adverse connections with school, society, and extended family.

Xena's ecomap (Figure 3.3) shows positive strong influences with husband, SPLT, child, and other children while weak vulnerable connection with friends and extended family. She has stressful and adverse connections with school and society.

Zafa's ecomap (Figure 3.4) shows positive strong influences with husband, SPLT, and the child while weak vulnerable connection with friends and other children. She has stressful and adverse connections with extended family, school and society.

Aena's ecomap (Figure 3.4) shows positive strong influences with husband, SPLT, friends, other children, and the child while weak vulnerable connection with school and society.

Bera's ecomap (Figure 3.5) shows positive strong influences with husband, SPLT, and the child while weak vulnerable connection with friends and extended family. She has stressful and adverse connections with school and society.

Cefa's ecomap (Figure 3.6) shows positive strong influences with husband, SPLT, and the child while stressful and adverse connections with friends, extended family, school, and society.

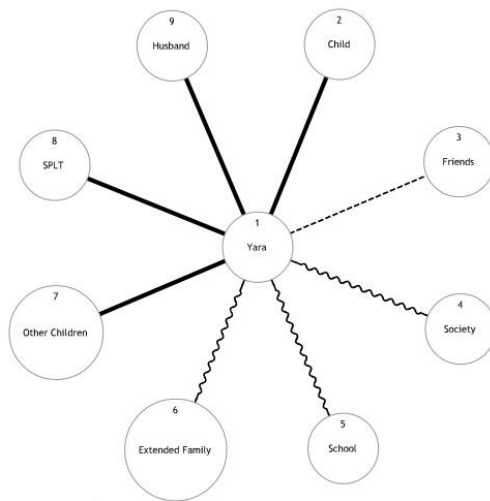


Figure 3.2: Yara's Ecomap

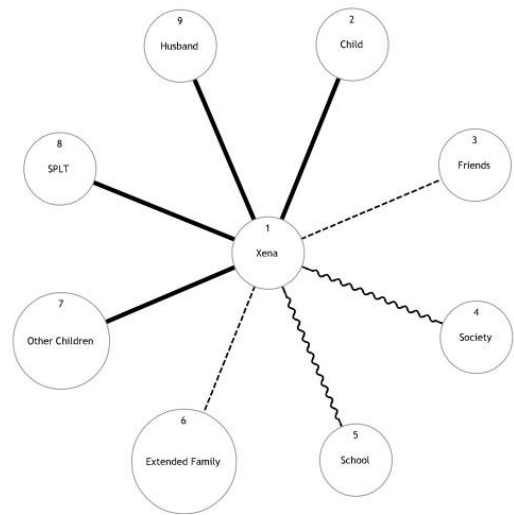


Figure 3.3: Xena's Ecomap

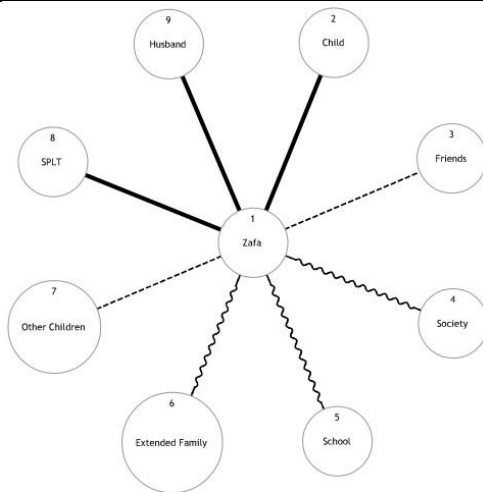


Figure 3.4: Zafa's Ecomap

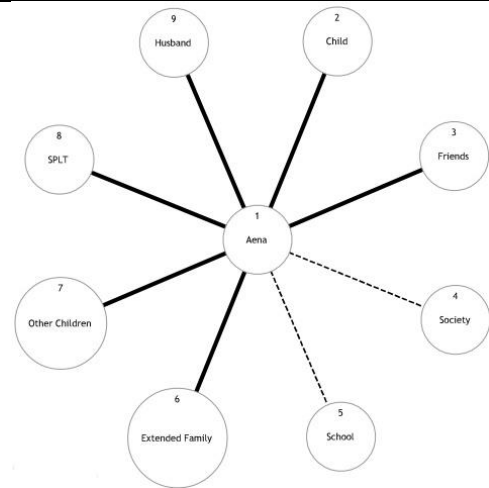


Figure 3.5: Aena's Ecomap

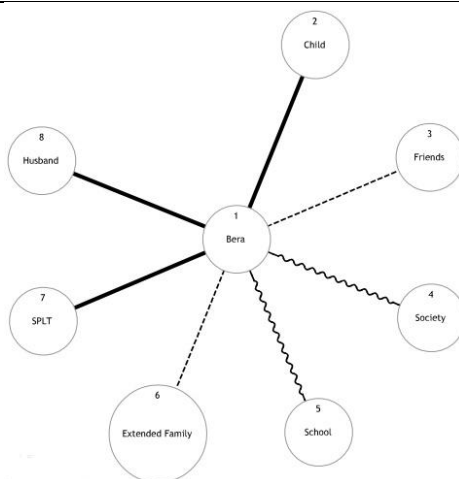


Figure 3.6: Bera's Ecomap

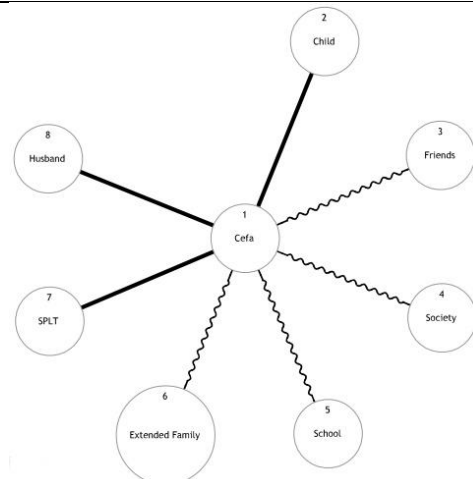
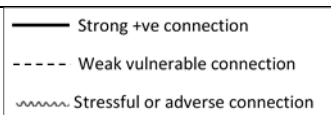


Figure 3.7: Cefa's Ecomap



3.7 The Interview Protocol

The interview protocol was not standardised but rather was self-designed based on the relevance of the research aim and objective. To do so, the researcher read extensively on the past studies on the experiences of parents raising children with autism. Before formulating the questions, the following suggestion by Yin (1994) was taken into account:

“... such a literature review is, therefore, a means to an end, and not –as most students think - an end in itself. Budding investigators think that the purpose of a literature review is to determine the answers about what is known on the topic; in contrast, experienced investigators review previous research to develop sharper and more insightful questions about the topic.”

(p. 9).

The other thing that helped in the process of designing the interview protocol was the researcher's experience treating children with autism and other related disorders. Furthermore, according to Yin (1994), differentiating and choosing the type of research questions is also imperative in research, that is considering the advantages of 'how' and 'why' in gathering information on people's life histories. Hence, the questions used were open ended, with the use of 'how' 'what' and 'why' questions.

The interviews were conducted using the interview protocol that was developed as a guide (Appendix 1), which has two parts. The first part involves preliminary questions related to selection criteria and the second part consists of three core questions. The interview protocol also has some sub-questions and probes. In general, the interviews were conducted using three fundamental questions. The sub-questions and probing were used minimally.

The primary interviews were done to the point of saturation which lasted about one hour and fifteen minutes with the participants who had the older children. The next three interviews lasted between forty to fifty minutes. After the initial analysis, a second follow-up clarification meeting was undertaken with the participants. The follow-up lasted about fifteen minutes. Two such follow-up interviews were conducted over the phone as they were not readily available for a face to face meeting.

3.8 Piloting the Research Instrument

Conducting a pilot study is one of the most appropriate ways to test some of the crucial factors of the research that is to be conducted. The pilot study also needs to be checked as closely as possible to the real research. The choice of participants for the pilot study should also ideally be selected from the target population (Glesne & Peshkin, 1992).

The questions for conducting the interview protocol were formed based on other previous research, and as well discussed with the research supervisor and colleagues. Following this, the tentatively formalised interview protocol for the interviewing was piloted on two participants drawn from the target population, prior to undertaking the research. In this process, few key aspects were considered.

Firstly, the appropriateness of the research questions and prompts in order to draw out the necessary data. Secondly, an assessment of the suitability of the possible interview setting, together with checks on the recording mechanisms to be used, such as tape recorder that was utilised for the data collection, were considered. Thirdly as qualitative research should be conducted in natural rather than artificial settings

(Scheyvens & Storey, 2003); the appropriacy of finding the best setting was considered.

After the pilot study, the interview protocol was discussed with the supervisor and was refined as needed. The most appropriate physical environment to conduct the interviews, within the natural context of the participants, was identified. The place that was found to be most suitable was the clinician's clinic setting as this was a place they have been visiting on and off, an area free from exposure to any significant others and the society. Thus, the anonymity of the mothers participating in the research was well protected, which gave the participants a sense of anonymity.

3.9 Data Collection

3.9.1 Data collection method

Individual interviews are most appropriate in social research when the area of investigation involves gathering information based on peoples' life experiences and feelings and information based on privileged, personal and sensitive issues (Descombe, 1998). Issues around a disability such as autism are recognised as a very sensitive area as it has emotional and social implications for the parents. Hence, individual interviews were chosen to be the primary data collection method to gather an in-depth understanding of the lived experiences of Maldivian mothers raising children with autism.

IPA can be conducted using both semi-structured as well as unstructured interviews. IPA depends on a flexible data collecting method; most IPA studies thus use semi-structured or unstructured interviews (Smith & Osborn, 2008). For the

purpose of this research, the unstructured interview was used in order to keep it more within the participant's natural voicing of their experiences as they feel meaningful to them. According to Smith et al. (2009):

“This approach also facilitates appreciation of the participants' priorities and sense of the relative importance of what the participants talk about and bring to the focus of the interview ... adopting unstructured approach also limits the potential danger of analysis merely reflecting the key topics identified within the interview schedule. It capitalizes upon IPA's ability to explore unanticipated and unexpected findings.”

(p. 70).

3.9.2 Data collection procedure

Smith and Osborn (2008) state that IPA interviews need to be guided rather than dictated, and the interviewer needs to have a general understanding of the topic researched, and also have set questions to get the interview going. When formulating the questions, in addition to the central question, a set of appropriate prompts and probing questions were also compiled to be used with the core question if needed. This not only helps in prompting or probing but also helps to funnel it down if required.

Using the central question first and then funnelling down is considered because according to Smith and Osborn (2008), if the interview is conducted in a reverse manner with a more specific question asked at the beginning, then there is a possibility of data getting biased towards the particular direction the researcher desired. As well, flexibility during interviewing was practised when required, thus allowing for an in-depth conversational style of an interview to happen.

Also at the same time, the suggestion of Smith and Osborne (2008), which is a “...good interview technique therefore often involves a gentle nudge from the interviewer rather than being too explicit” (p. 61) while conducting IPA interviews.

Direct questions or a probe were used only when necessary as not to disrupt the participant's flow of conversation as long as the conversation is relevant and within the boundaries of the research topic.

The order of the type of questioning was pre-determined to a certain extent in some form of logical manner to be used if needed. As mentioned above, the questions were planned from general to more sensitive since the participant can benefit from relaxing into the interview situation before having to answer a possibly sensitive question (Smith & Osborn, 2008). Descombe (1998) states that it is not unusual for sliding back and forth when using interviews when trying to get an in-depth understanding of the experiences of peoples' lives. Thus, this technique was applied as needed. The most fruitful way that the researcher found was to ask the most sensitive question half way through the interview. This method worked very well during the interviewing.

According to Laws et al., (2003:274), when people are asked questions, the depth and the truthfulness of the answer can be dependent upon several factors such as the setting in which the interview is conducted, and or on factors such as how safe the participant feel with the researcher. Therefore, factors that enhance successful interviewing and data gathering were considered. One such issue is termed by Glesne and Peshkin (1992:93) as issues of 'personal dimensions', such as building rapport with the participants and the personal subjectivity of the researcher. Dawson (2007) also stresses the importance of building a good relationship with the participant because people need the receiver of the information as someone whom they can trust if they were to reveal their very personal information. Therefore, building a good

rapport with the participants was considered as one of the key factors to successful in-depth interviews, which is the objective of the data collection of this research.

In this interview process, it was found that the issue of ‘trust’ and ‘anonymity’ was the most crucial component in getting the in-depth interview. An issue the researcher thought of, but one that alarmed the researcher during the interviews, since the researcher’s pre-assumption was that mothers would be more desensitised to some sensitive issues. Participants were willing to share information, but only with the guarantee that the anonymity will be kept at all times, even at the cost of leaving valuable information of the research objective out if it is thought to hinder or in any way disrupt harmony in their lives. Even those mothers whom the researcher has worked with for many years, and thought would be okay, had some reluctance as it will be a thesis rather than their clinical case notes which have always stayed confidential.

But having said the above, after the researcher had given them the guarantee, they had no problem talking through their whole journey with its many ups and downs. The researcher was humbled and happy that the participants were willing and shared their innermost feelings and stories of their difficult journey, accepting and respecting the researcher as someone who can do them justice and keep the anonymity. The researcher believes that this level of trust has come out of years of professional and somewhat personal bond the researcher has with them through the years of her clinical practice. Moreover, it may also be because the researcher as a clinician has always kept an ethical, confidential, and professional career.

After all, it's 'our journey' too, a journey which has bonded the mothers of children with autism whom the researcher has some level of relationship even after years of stopping direct therapy. Also, as the researcher is still continuing to work with some of the participants, the researcher did all she could to not make them feel intimidated through the interview process. At the same time, it is fair to note that as mentioned above a good level of rapport was needed at a personal level, to draw out the in-depth information required for the research and also be able to keep further contact for the member check and a possible second interview after the analysis.

Due to the above mentioned concern regarding anonymity, the researcher can see her handcuffed such that the researcher literally had to do the translating and transcribing of the lengthy verbatim alone, as some significant information that they may have spilled out through 'comfort talking' be removed before it is seen by anyone other than the researcher. The researcher has promised them to do so and as well get them to confirm the general overview of the chosen parts of the verbatim transcriptions for their consolation. From this, the researcher has come to realise as a researcher that all small communities such as Maldives can have its sincere and valid limitations while sharing some sensitive information about a clinician, a friend, or a family member. The researcher can relate to this as highly accurate as being a Maldivian herself, been brought up in such a close-knit society like the Maldives.

The researcher did try, maintaining a balance and not forming what Glesne and Peshkin (1992:93) termed as 'over-rapport' or friendship as much as possible in order to circumvent any situation that may bias the research data. This aspect was constantly thought of and addressed since the researcher herself is one among the limited professionals practising in the country. On the positive side as Smith and Osborn

summarise “...it facilitates rapport/empathy, allows greater flexibility of coverage and allows the interview to go into novel areas, and it tends to produce richer data. On the debit side, this form of interviewing reduces control the investigator has over the situation, takes longer to carry out, and is harder to analyse” (Smith and Osborn, 2008, p. 58). The questions were natural, non-leading, and open-ended, with minimal professional jargon, complying with the guidelines of doing IPA by Smith and Osborn (2008).

3.10 Data Analysis

In studies that require in-depth understanding, the data analysis cannot be separated from the data collection, since one should always be considering the aims and focus of the research and then identifying ways to make sense of the data (David & Sutton, 2004; Laws et al., 2003; Mason, 2002). Hence, throughout the interviewing period and even after the field work, how the research data was analysed and interpreted was carefully thought of.

As explained above, the data was collected using individual interviews. The data are taped records of the interviews conducted, in conjunction with the informal diary notes (observations) taken at different points during the interview. The memos made were later linked when listening and transcribing the tapes which are stored as raw data (Wengraf, 2001). The informal diary notes which consists of observations of the participants such as pauses, reluctances, facial expressions and even tearing or crying on and off through the interview have helped the researcher with a deeper understanding of their voices in the translation and transcribing process. The interviews were translated and transcribed following the interview transcribing

methods explained by Smith, Flowers and Larkin (2007) for IPA analysis. The key requirement of IPA transcription is ‘a semantic record of the interview; that means a transcript showing all the words that are spoken’, and the non-verbal utterances such as laughter, significant and pauses hesitations are bracketed as a note rather than coded representation (Smith et al., 2009).

According to Smith et al., (2009), IPA is ideographic in nature. It should be started with the description of one single case and is recommended to start with the most complex, detailed and engaging case. The first step in IPA involves immersing oneself deep into the data and read and re-read until you get a real insight into the case. Then, go on to subsequent cases. IPA is also inductive in nature thus allowed ideas and themes emerge rather than imposing a theory on it during the analysis process.

3.10.1 Analysing process

For the purpose of this research, the translated verbatim transcripts of the individual interviews were interpreted using IPA analysis guidelines as suggested by Smith et al., (2009); as given below which consists of six distinct steps which further followed into the deepest level of interpretation, the ultimate essence of an IPA. The researcher have discussed the process that she followed under each relevant step below.

- 1) *Step 1: Reading and re-reading.* As per the guidelines, this first phase involves immersing oneself into some of the data by reading and re-reading. Hence, the researcher first read the three sets of data which seemed to be the most engaging. These were the data from the three participants who have had the longest years of experience. During this stage of the very first reading, the audio tapes were used in the attempt of immersing and engaging with the data. After the first

reading of these three sets of data, then the researcher selected the set of data which she felt is the best one to immerse herself in, in the hope of entering the participant's world. Once this was achieved, the researcher went on to the next step.

- 2) *Step 2: Initial noting.* This move of the initial noting is the action in which the researcher became more familiar with the participant's world. Initially, the researcher was reading into data by examining the semantic content and language use which help at an exploratory level. The researcher tried her best not to be superficial as guided as she kept noting the descriptive comments which may later form an emergent theme. This was done on a landscape table which had the raw data in the centre column with two columns on either side. One for exploratory comments and the other for use to note emergent themes as and when needed. Furthermore, as the researcher became more familiar with the participant's world, she looked into linguistic comments which helped her to have a deeper understanding of the participant's experience. Like this, the researcher went on to do the initial coding of the first three sets of data that she had chosen as the most engaging. After completing the three sets of data with the exploratory comments then she went on to the next stage.
- 3) *Step 3: Developing emergent themes.* This process involved moving from initial noting towards the analysis, hence concentrated on the exploratory comments to look for some emergent themes. As can be expected the data started getting re-organized as the themes started emerging. From here on the hermeneutic cycle had begun. The themes then started reflecting the phenomenological meaning.
- 4) *Step 4: Searching for connections across the emergent themes.* In this step as the heading states, it involved looking for connections across the emergent themes, which included a process of charting and mapping. In the course of looking for

patterns and connections between the emergent themes, abstraction was primarily used followed by subsumption in coming up with the super-ordinate themes.

- 5) *Step 5: Moving to the next case.* After completing analysis of the first three sets of data, giving each case its due respect, keeping in mind the idiographic commitment of IPA in allowing new themes to emerge. Hence, deliberate care was taken to follow steps 1 to 4 for each set of data. Then the researcher went on to the step 6.
- 6) *Step 6: Looking for patterns across the cases.* In this stage, the researcher took the first three cases and looked for patterns across these three cases before going on to the other three cases. Finally, after the analysis of all six cases was completed with the themes, and forming the super-ordinate themes, which were in the form of separate but connected themes and phases.

3.10.2 Talking it deeper: Levels of interpretation

The researcher had carefully considered doing justice to IPA as a methodology as much as she could. According to Smith et al., (2009), novice researchers have an inclination to be too cautious in the analysis process. As a result, the analysis becomes more descriptive than interpretative. As the researcher is a novice researcher to IPA, she has done her best to spend sufficient time and rigour in following the steps as guided by the book 'IPA: Theory, Method and Research' by Smith et al., (2009).

3.11 Ethical Considerations

Ethical considerations is an integral part of any research and it is an aspect that needs to be followed throughout the research process, starting with data collection and

analysis through to the writing up of the research (David & Sutton, 2004; Goodley et al., 2004; Laws et al., 2003; Mason, 2002). According to Merriam (2002), the ethics of the research to a large extent helps in the validity and the reliability of investigation.

Ethical considerations relating to research involving families with children with disabilities should not be overlooked (Benderix et al., 2007). Thus, several issues were taken into consideration in the research process, from the beginning of the research preparation stage through to data collection, analysis and in the write-up of the study. One among this was informing and getting approval from the University Ethics Committee, and informing the concerned authorities in the country of research participants.

Maximum measures were taken to protect the research participants' anonymity at all levels. Firstly, signed informed consent was obtained before the individual interviews were done (see Appendix 2 for sample of the consent form). Berg (2007) states that getting written consent with a name and address can itself be a serious threat in protecting the anonymity of the subject. Thus, the involvement of no other people such as assistants is considered in the interview process. This thus allowed the assurance of a high degree of confidentiality to the participants of the research. Hence, all interviews were conducted by the researcher personally.

The participants were made aware of any issues of concern at the point of obtaining the informed consent (Glesne & Peshkin, 1992). The respondents were also informed of their rights such as the right as a participant to continue with the process or withdraw from the research at any time if they feel uncomfortable (see Appendix 3 for the sample of 'information' sheet used for this purpose).

Secondly, the interviews are conducted in ‘Dhivehi’ (mother tongue) of the researcher and the participants in order to make the interview process comfortable for the participants. Therefore, the interview material had to be translated into English. Due to the anonymity issue discussed above, the most sensitive interviews were transcribed by the researcher and the less sensitive ones by one single person chosen by the researcher who has given consent to respect the participants request to anonymity.

According to Scheyvens et al., (2003), the researcher is obliged to keep the anonymity of the participants if they are asked to do so, which was one important issue raised by the participants. According to Laws et al., (2003), protecting anonymity, when undertaking research in small communities can be a tough situation and in many instances, it is even unrealistic. Therefore, the researcher has taken significant measures to protect the anonymity of the participants in the study, by bearing in consideration every measure possible to ensure their anonymity within such a close-knit community (more detail on this issue discussed under data collection).

For a local researcher, undertaking home based research can have its many advantages but is also not immune from having its share of disadvantages (Leslie & Storey, 2003). Since the researcher is a local from the research community, issues such as conflict of interest that can arise in home based research or other political matters that may act as difficulties within research process have been considered (Scheyvens, Nowak & Scheyvens, 2003). Such issues have been discussed with the supervisor as to avoid any such difficulties and to enhance knowledge in order to be prepared for handling such issues as smoothly as possible.

CHAPTER 4 : FINDINGS

4.1 Introduction

The purpose of this Interpretative Phenomenological Analysis (IPA) is to explore the lived experiences of Maldivian mothers raising their children with autism. The study aimed to get the essence (the deeper meaning) of the mothers' lived experience in raising autistic children. As discussed in Chapter Three, IPA is a methodology that can capture the deeper meaning of how people make sense of their world by interpreting their own experiences, when faced with challenges of life (Flowers, Larkin and Smith; 2009).

The meaning of the lived experience of six mothers in raising their autistic children is captured below by analysing the in-depth interviews done with the mothers. The findings are presented as a journey-in-progress that consists of four distinct, yet connected, stages. Stage One of the journeys is the beginning in which mothers' intuitively become aware of their children's communicative, behavioural and social differences up to the point of getting a diagnosis. Stage Two is characterised by the challenging process of accepting the diagnosis and seeking treatment. It included searching for appropriate schooling and hoping for a cure. Stage Three is when the mothers finally faced the reality of the 'life-long' nature of autism and undergo a 'metamorphosis of self' in order to be able to continue their journey in a meaningful way. Stage Four is the mothers having transformed themselves, eventually come to accept the chronic nature of their children's condition and completely commit themselves to the never-ending journey. The many features of the phenomenological meaning of raising an autistic child are included in this phase of the lived experience.

Pseudonyms Xena, Yara, Zafa Aena, Bera and Cefa are used below to protect the identity of the participants. Before I go into the analysis, I would like to bring to your attention that though the participants of this study are homogenous in many ways, there is a difference in the years of experience they had in raising their children with autism (see for further detail in Chapter Three, under the heading Participant Selection). The mothers, Xena, Yara and Zafa having experienced over 12–15 years of experience in raising their children with autism seems to have gone through all the four stages of the journey. Whereas, the mothers Aena, Bera and Cefa have much younger children. They have experienced less than six years of raising their autistic children seems to have gone through only the first few stages of the journey. Hence, Xena, Yara and Zafa will be treated as primary participants of this study and the mothers with younger children, Aena, Bera and Cefa as the supporting participants. The analysis of each mother will be analysed under the appropriate stages.

4.2 Phase 1: Intuitive Maternal Diagnosis

The mothers in this research have sensed a difference in their child very early on in the children's life. They had sensed both communicative and behavioural deviances in their children. This sensing is strong enough for the mothers to be sure that their children are different and have deviated from the normal development. They also seems to have made some 'intuitive maternal diagnosis' and has persistently worked to get the problem their children have solved by reaching out for professional help. For some mothers, it has been easier to get a diagnosis but the others had to go through a long process. An interesting phenomenon in this phase is that the mothers having made their intuitive diagnosis, though unaware of what exactly it is, have not given up in

their search for getting an answer until they were satisfied by getting a proper diagnosis.

4.2.1 Sensing a difference in the child

The very first significant milestone in the mothers' journey of their lived experience of raising autistic children is becoming aware of the children's characteristics when compared to other kids. This awareness is conceptualised as the 'starting point' of the journey; it is the conjuncture in which mothers begin to sense one's child deviating from the norms of child development that are familiar to them. Mothers' sensing of such differences in their autistic children seems to be due to an intrinsic, or natural, interest, inherent in them to compare their children with other kids; autistic children are sometimes compared with one's children, and also with children of friends and family. According to Xena *"When we see the difference compared to other kids then we, parents will notice it eh?"* Similar sentiments were shared by Yara *"... [child's name] had a cousin that is close to her in age, um the cousin started talking but my child has not so then I realized there are some delays in [child]"* and Zafa as well *"I knew something was wrong because he does not give eye contact and as well he will not give attention to anyone"*.

Sensing of such differences falls into two areas: delay in speech development and deviance in behavioural norms. These are presented below.

4.2.1.1 Sensing delay in speech development

Such first deviation or difference mothers detected are that their children were deviating from the norms of speech development. For example, Xena recognised the lack of speech development at an early stage of her child's development. She said:

“Around 1 ½ years of age I did notice that he is having a problem because his words were not increasing as it should, just realised there is some problem”.

(Xena, Clinic, 19/3/15)

A similar delay in speech development was recognised and voiced by Yara. She said:

“I realised it because she was not talking, um, I mean she did not start talking at the age children normally speak, and she did not say anything, not a single word at that age”.

(Yara, Home, 05/04/15)

Aena also had sensed a difference and a speech delay when her child was as young as two years. She told:

“At the age of 2 years we had a suspicion and consulted to a psychologist, but the doctor said ... don't want to say [child] has autism. We told him that [child] has delayed speech”.

(Aena, Clinic, 17/03/15)

4.2.1.2 Sensing behavioural differences

In addition to speech delay, mothers also became aware of certain behavioural deviances in their child. For example Aena further added:

“... we told him that he has delayed speech, and have no eye contact and behaves different”.

(Aena, Clinic, 17/03/15)

Xena also has noticed several behavioural differences in her child. Xena said:

“We kept noticing there are some difficulties with the child, like certain sounds he makes while playing, like humming sound, continuous body rocking, also interests such as special liking to things like wheels, fans, and spinning things ... [child name] ... Actually, both my husband and myself, we were both feeling that there is a difference in his behaviour too. It was not just language”.

(Xena, Clinic, 19/03/15)

Similar sentiments were echoed by Zafa and Bera as well. Zafa said:

“... he does not give eye contact and as well he will not give attention to anyone ... [child name] ... He shook his head all the time and if we give something to him also he will not make eye contact”.

(Zafa, Clinic, 21/03/15)

Bera also has noticed differences in the child's behaviour such as not giving eye contact and hence have consulted the child specialist. She said:

“About one year four months we consulted with the paediatrician and discussed with him, regarding [child] problems, not responding, no eye contacts all these things”.

(Bera, Clinic, 21/03/15)

At first, this sensing of differences in their children was a concern that motivated them to seek answers, without knowing the cause of the difference. As Zafa said:

“Yes, from that time we noticed that he is different. But we don't know what it was”. Similar feelings were shared by Xena in saying that “Later around 2 ½ or 3 years of age ... [child name] ... err we noticed autism-related symptoms difficulties, but at that time, we did not know it was of autism ... hmm, we only knew there were some difficulties”.

(Zafa, Clinic, 21/03/15)

Aena also knew that her child is not normal as she kept noticing the differences and said:

“Yeah, anyway we didn’t know what autism really was; only what we knew was he did not have eye contact and did not respond to us. Also, he was very busy all the time messing up things at home”.

(Aena, Clinic, 17/03/15)

4.2.2 The potency of maternal instinct, leading to a diagnosis

What began as a mere sensing of differences in their children, eventually became a much deeper and compelling concern as mothers kept seeing specific deviances in their children. They knew that something was not right, and kept on looking for answers. In the process of searching for answers, they eventually arrive at their differential or intuitive diagnosis, by ruling out certain general conditions such as hearing impairment. Zafa expressed such intuitive diagnosis:

“Some people will say maybe he is deaf and dumb. But we know he is not deaf, sometimes he gives attention to prayer call and goes out to the balcony to see the vehicles on the road”.

(Zafa, Clinic, 21/03/15)

The period of living with their ‘intuitive maternal diagnosis’ was neither worry free nor long lived. Over time, the mothers’ concern for their children, together with the consistent observation of the norm differences and the desire to seek answers drove them to seek a professional opinion. Xena has gone through such a process and said:

“Later I realised vocabulary was not increasing like other kids do as I said before. So, we consulted doctors in [a South Asian country] and as well as in [another South Asian country] too. But nothing was diagnosed at that time either. The doctors said there was nothing to worry and some children may take a time to start speaking. So, it went on like that”.

(Xena, Clinic, 19/03/15)

The first attempt of seeking professional guidance achieved mixed results for these mothers. As the quote above indicates, Xena did not succeed in obtaining a diagnosis on her first attempt to seek professional advice. On the other hand, Yara received an appropriate guidance from the doctor regarding her child's speech delay.

“At that same time (of having a concern regarding delayed speech) my child also was suffering from another illness. So we had to go abroad [South Asian country] for that, for some allergic problems. On that trip, when we consulted the child specialist, that day the child specialist recommended, that doctor recommended us to go and consult a child psychologist to make sure. Then we went and consulted a child psychologist. That day the psychologist did some informal assessment and said that his closest guess was that my child is suffering from mild autism”.

(Yara, Home, 05/04/15)

This observation was noted in my field notes: “As Yara voiced the above she took a deep breath and appeared somewhat tensed. She seemed to be holding herself from tearing as though she was reliving that trip and what happened that day” (interview and observation: 05/04/2015). Bera also has had an appropriate referral after seeing the diagnosis which leads to the getting the final diagnosis. Bera added,

“He advised us to consult with the psychologist ... [child name] was about one year eight months when we could consult the psychologist. She told me that [child] was having the features of autism”.

(Bera, Clinic, 21/03/15)

Whereas in Zafa's case it was seen that the doctor, although have mentioned the world' autistic have not given a proper diagnosis or a clearer more appropriate guidance. Zafa said:

“Actually some time before, the child specialist said that he may be an autistic child. But did not say much. Said we have gone abroad to check”.

(Zafa, Clinic, 21/03/15)

Cefa seems to be the luckiest in getting a diagnosis with the first consultation.

Her experience was:

“I went to the doctor because [child] was different. Then the doctor diagnosed [child] as autism”

(Cefa, Clinic, 17/03/15)

4.2.3 Enduring for a diagnosis and treatment

While Yara obtained a diagnosis and referral to a speech therapist, Xena did not obtain a proper diagnosis or professional help following the first visit to the doctor. Aena also had to go to the specialist many times before she finally got her child diagnosed. In Zafa’s case, it was ambiguous for the mother as can be seen above. Hence, there was a delay in diagnosis and treatment for Zafa’s child as well.

Data shows that most mothers kept struggling to find answers for the condition of their children. This drive for professional treatment was compelled by their instinctive diagnosis and motherly love. The sheer persistence of the mother, as can be seen in Xena’s, resulted in her pursuing the guidance of friends and family and arrived at a conclusion of seeing the speech therapist. She said:

“We err ... we even discussed this within our family, we discussed some of his difficulties, when we discussed we came to a conclusion to consult the speech therapist [therapist’s name, We decided it will be good to consult the speech therapist as what we notice most and concerned was his language problems. Not in the order, but we went to different places around then. But there again they have also concluded like before, saying it is just a delayed speech and nothing else to worry. All the general tests were normal, like perfect hearing, attention to sounds, etc. In [a neighbouring country] they said it was just delayed speech. What we have got from all the specialists from different countries was that my child is normal and it was just delayed speech and there are few children who take time to speak”.

(Xena, Clinic, 19/03/15)

Aena also seems to have gone through a long process of trying to get her child diagnosed to the point of having to depend on media and friends. She talked through her journey and said:

“Yeah, anyway we didn’t know what autism really was, only what we knew was [child name] did not have eye contact and did not respond to us, also [child name] was very busy all the time messing up things at home. One day we heard on a TV program about autism and the symptoms, suddenly I felt it is the same symptoms that my child is having, so better to consult somebody to get it diagnosed. I went to a person and told what was highlighted on the TV program, and he told me he couldn’t say it is autism as he was very young, but there is sure a delay in speech so keep on talking to him [child name]. So according to the doctor’s advice, we tried to talk to [child name] for 3 months, but [child name] was not responding. Then, one day I met my classmate in a shop, and she asked me about my child. I thought I will tell her about [child name] this time, which I had not shared with anyone before. So I told her about [child name], and she said the same is happening to her child and she takes her child to a special psychologist and she is excellent. I told her about the speech delay and she told me there is a speech therapist who can take care of that. I got the speech therapist contact from her [...] I went to the speech therapist. The speech therapist is the one who told me that the child is having symptoms of autism”.

(Aena, Clinic, 17/03/15)

Zafa also had finally gone abroad to get a diagnosis as the child specialist indicated that her child may have autism.

“Then we waited and later went to a (neighbouring country). Then, from there the said my child has autism”.

(Zafa, Clinic, 21/03/15)

As a result of not been able to get appropriate guidance or diagnosis, most mothers have lost time by waiting, going from one specialist to another, from one country to another, to get their children diagnosed. It took Xena a good few years to get to the point of contentment with receiving an appropriate diagnosis.

“I got diagnosis years later, about six years. Yes, he was about six years umm ... I think between 6 and seven years then”.

(Xena, Clinic, 19/03/15)

Finally, the determination of the mothers fuelled with their firm intuitive diagnosis lead the mothers to get their children's condition diagnosed. What followed as can be seen below in the second phase of the mothers' journey was not any easier for them either.

4.3 Phase 2: An Uphill Battle

This phase of the journey was no easier than the beginning for the mothers. Rather the difficulties and the challenges the mothers encountered seems to be double folded. On one hand, they were faced with the reality of facing the diagnosis of a long term disability of their children and at the same time racing against all odds to get their children the required treatment. Hence, the mothers had to simultaneously deal with their own emotions and at the same time go in search of getting their children the appropriate treatment. This phase of their journey appears to be an 'uphill battle' encountering different hurdles as they went along. These hurdles are analysed and grouped under three subheadings: facing the reality of the diagnosis, searching for treatment and learning to deal with the challenges of schooling.

4.3.1 Diagnosis

Facing the reality was accompanied by mixed emotions. The period that the mothers received a definite diagnosis showed assortment of emotions. For one mother getting the initial diagnosis came as a relief as it's an answer for what she was worrying for years. For another mother obtaining a diagnosis of such an unheard chronic condition

first was of shock and disbelief. The more significant emotion common among mothers was the feeling of sadness as the reality of the challenges and implications of autism unfolded in front of their eyes.

4.3.2 Shock

The initial diagnosis came as a shock to Yara. Hearing a new word, a condition she had never heard of, the unknown, was an immense shock. A shock accompanied by several questions for which she needed answers for. While she talked through about the period of initial diagnosis she seems to be reliving the moment of shock, repeating herself saying as to how new and shocking the word ‘autism’ was:

“That is the first time I heard the word autism ... before that I never knew what autism is, what is it like, whether this is something in the world, I mean if other children have had it or not, how did this word come, what is this about, what happens then, I had no clue of what autism is about, have not heard of this ever ... That is really when first I heard of this word autism. On this day, I paused for a minute and then asked the doctor what autism is, what it is. Then the doctor explained a bit saying so and so is the delays and features and in this disorder and as far as the doctor can say my child is autistic”.

(Yara, Home, 05/04/15)

4.3.3 Disbelief

Yara’s initial shock also lead to disbelief, she seems to have needed a moment to digest what she heard. She also needed verification for what she heard before she could accept such an alien word as a diagnosis about her child’s condition.

“Then I asked the doctor, what are the features that you mean? Then the doctor said eye contact and um hyper ..., actually the doctor gave three main features. One feature was hyperactivity; the second one was poor eye contact and third was speech delay”.

(Yara, Home, 05/04/15)

As a result of this disbelief, Yara had found herself questioning and wanting to clarify. Hence, Yara seems to have on the spot validated what the specialist has told her by comparing her child's features along with the specific features that was highlighted as autistic features:

“Then I had a good think about my child. I realized these three features were in my child. So then I asked the doctor what I can do, what is the treatment for this? Then the doctor said, I have to look for and find a clinical psychologist and a speech therapist”.

(Yara, Home, 05/04/15)

4.3.4 Denial

Later the shock and disbelief were taken over by denial in the case of Yara. As a result, instead of hundred percent accepting what she had heard in spite of having validated that her child has autistic features, she went for a second opinion as a means of reassurance. Yara said:

“After coming back, even without saying that some doctor has suggested my child has autism I checked at home to see if there were people I can show, so went and showed them. ... [] ... Then after the assessment the clinical psychologist gave the same diagnosis that my child has mild autism. After that, I showed her to the speech therapist ... [] ... The speech therapist also said my daughter has mild autism. From then on I accepted that the delays my daughter was having were because of autism. From that point we started her treatment”.

(Yara, Home, 05/04/15)

In the case of Zafa, she has not been able to voice clearly if she was in disbelief or denial. But as can be seen from the interview quote:

“[Child name] was diagnosed as having autism in (neighbouring country) ... [] ... Then again, we came home and went to the child specialist and he advised us to go to the speech therapist...” (see below under sadness), she seems to have not fully embraced the diagnosis when she received it from abroad. Her true emotion associated with the diagnosis appears to have been surfaced after seeing the second specialist who gave her a clearer picture of the possible challenges for her child”.

(Zafa, Clinic, 21/03/15)

4.3.5 Relief

For Xena, a mother who have sensed her child's condition for years without a proper diagnosis, the initial diagnosis came as a relief, a consolation.

“In a way it was a relief, a kind of satisfaction that we finally have found out what was the problem ... exactly what was his problem and the difficulties he has”.

(Xena, 19/03/15)

But as can be seen below Xena's initial relief turned into sadness.

4.3.6 Sadness

The most dominating emotion for all three mothers in this study was sadness. In Xena's case, the relief she felt as she got a proper diagnosis after years of struggle, was short-lived and replaced by sadness as she started empathising with her child's condition. Xena said:

“But naturally as parents we were sad. From that point, we had started gathering information about autism, how the child feels and how they react and their inner feelings and all this information gathered from books and doctors as we had no internet access at that time. It was disturbing and sad to know what and how children with autism feel and react. Also, he can express his feelings. But first, we didn't know. So, there were sad moments, even I got emotional too [a soft laugh]”.

(Xena, Home, 19/03/15)

As Xena expressed the above sentiments, I observed that she seems to be living through the period in which she could not figure out her child's difficulties and seems to have a sense of remorse in addition to sadness since she was unable to help her child more appropriately. This observation was noted in my field notes: *“The mother showed sadness accompanied by a sense of guilt and uneasiness in her voice while she talked through, at that point I could sense a mixture of remorse and pain as she swallowed her words with a soft laugh”* (Interview and observation: 19/03/15).

As mentioned above for Zafa, sadness was not instant emotion as she first received the diagnosis from the abroad possibility as she had not understood what her child is having autism meant. But rather a pang of sadness for her came much later after hearing the implications of autism on the child's future development. She said:

“[Child name] was diagnosed as having autism in (neighbouring country) ... [] ... Then again, we came home and went to the child specialist and he advised us to go to the speech therapist. Those days a speech therapist was working only at (name of hospital). From there we got more information and came to know that these difficulties are not that simple, it may not be cured completely, and he possibly may not be able to study even as normal children. That was very sad news which I did not expect to hear. So I cried a lot that day”.

(Zafa, Clinic, 21/03/15)

Aena and Bera also felt sadness with receiving the diagnosis of autism. Aena said immediately after diagnosis *“I was very sad and started taking speech therapy”*. On the other hand, Bera's sadness was also accompanied with some guilt as she had voiced *“first when we came to know the problem, we were very sad and thought this may happen because we couldn't take care before”*. Cefa's sadness was followed by the diagnosis as she got the information that the treatment that is needed for her child is not available within their home setting as can be seen by searching for treatment.

An interesting finding at this phase was that though the mothers have shown varying emotions of relief, shock, denial and sadness, they do not seem to show clear signs of grieving. They seem to have got hold of their emotions and soon after gone into action. The next step was that the mothers immediately started searching for the best possible treatment for this challenging condition called autism. One possibility of no real signs of grief may be because of the driving force that has pushed the mothers towards seeking treatment in the hope of the cure for their child.

4.3.7 Seeking treatment: ‘a run’ through a barren desert

Immediately after the diagnosis, mothers have gone in search of the treatment, the cure, for their children. In this process, they had to face a tough reality, which is the treatment they are looking for, what their children needed, was not readily available from the home country. Even the mothers with younger children have also experienced the difficulties in the treatment process.

An interesting finding here is that none of the mothers were willing to stop at that point. They had gone to the extent of searching every corner within the home country for the possible choices and even travelling the world in the hope of getting their child the necessary diagnosis and treatment. The driving force behind the mothers seems to be their desire to help their child to get better.

Having said the above, the reality of going abroad in search of treatment was in itself an uphill battle against all odds; especially having to face financial difficulties can be seen with Xena. The difficulties had resulted in years of delay before they could get their child the treatment that was required:

“The full treatment we could only give him at the age of 12 years due to financial difficulties. We were only able to go with the help of other friends as well. We were able to go to [South Asian country] to get the treatment at [Clinic name]”

(Xena, Clinic, 19/03/15)

Having been told that the treatment their child need was unavailable within the country and financial difficulties to go abroad has also been voiced by Cefa. Cefa said:

9876“... that doctor said you have to go abroad for the treatment, it cannot be treated here in Male’. I was very sad and tears came from

my eyes that moment. My husband said it was not possible as we were financially not very good”.

(Cefa, Clinic, 17/03/15)

Also, the challenges the mothers faced didn't stop by going abroad either. Living in a foreign country had its share of difficulties for the treatment process along with the previously mentioned financial constraints. Hence, though the treatments were available in those countries, it had not been easily sustainable. According to Xena:

“This was continued for over 1 ½ years, and he had benefited a lot within this period. Treatment was done with speech therapy along with education with the clinics help ... []..... after staying there for that 1 ½ years, from there later they said there is nothing much they can do there anymore, he is moving on well and the major area to work on then was his social skills, but as we were in foreign land it was not easy to work on his social issues. So we thought it will be in a way better to move back home, because I thought then only the social skills will improve. So due to both financial difficulties and for this other reason we had to come back home. Since then we are living her at home”.

(Xena, Clinic, 19/3/15)

Just as abroad the challenges the Xena faced continued even at home. Hence she had to address the challenges and accept the reality and did what best she could under the circumstances. Xena continued:

“Since we are here back home, especially after getting the diagnosis of autism, we have never come across any place, a clinic or even a single specialist of autism. Regarding my son's condition, the only treatment we could give him at home here was speech therapy, for all the other difficulties he had, we were unable to get any other treatments here. We couldn't get any help for him which he needed, except for speech therapy”.

(Xena, Clinic, 19/3/15)

In case of Yara, she seems to have faced her share of challenges. Unlike Xena, Yara was initially forced to settle for the treatment that was available from the home country. This was not emotionally comfortable for the mother either, knowing that her child is not getting all the necessary treatments that the child needs. According to Yara:

“The saddest thing was that the first thing she needed was early intervention from an occupational therapist, but there were no occupational therapists in the country. So we found that very hard. But somewhat got some input and help from the clinical psychologist’s clinic. Because at that time there was a therapist from [abroad] at that clinic. I think that person had some training in occupational therapy. It was not sufficient but we did get some help and guidance of that therapist with regard to occupational therapy exercises, I mean we got some help. Speech therapy was not a problem. We consulted [therapist] and got speech therapy from the speech therapist at the hospital”.

(Yara, Home, 05/04/15)

Getting the appropriate treatment for their autistic children had been a difficult process for all mothers. Similar vibrations, which is knowing what treatments their children needs, the inability to provide the different treatments that were required except for one form of therapy, was not an easy task for Zafa, Aena and Bera either. Aena and Bera voiced similar concerns and have said respectively:

“It was limited treatment here at home, especially behaviour therapy was not possible at all’ and “behaviour therapy is what I really needed at that time for my child but I couldn’t before as it was not available”.

(Aena, Clinic, 17/3/15 & Bera, Clinic, 21/03/15)

The only available therapy that Zafa’s child was getting at that moment also got discontinued. Zafa continued in a soft and sad manner:

“We went to get speech therapy but after a while the only speech therapist available got sick and treatment got discontinued. So he was at home without any therapy as there are no other alternatives. We did work as best as we can as guide by the speech therapist before she stopped ... Then after 2 ½ years, we heard from the speech therapist again ... [] ... Despite not having any specific

therapy, we did all we could do and gave him a lot of attention ... []
... No other treatments were given, not at all. Behaviour therapy or
any other therapy needed we could not get”.

(Zafa, Clinic, 21/03/15)

This phase of the mothers’ journey, providing their children with the treatment, was embedded with difficulties and challenges. In addition to this, mothers also were faced with further challenges of schooling for their autistic children.

4.3.8 Learning to deal with the challenges of schooling

Education and schooling are part of children’s growing up. It has become an integral component of the cultural and societal norms in most countries in the world. It is also highly critical for children with special needs. The participants of this research, mothers, also had aspirations for their children to go to school like all other kids.

“At that point we decided if we take him to that school in uniform,
he will also feel that he is going to a school like other children”.

(Xena, Clinic, 19/03/15)

For all the mothers, the possibility of finding a school or a class that their children can fit in had its share of challenges just like while seeking the necessary treatment for their children. There was no easy path for schooling either. Mothers who went abroad looking for treatment had tried special education in those countries too. But over time, they also found that the school and the services were not right for the children as mothers desired. The process of schooling was packed with emotional hardships and situational challenges both in the home country and abroad for all mothers. In this process, Xena was forced to opt for home schooling due to the challenges that she had to face with. Xena talked through her experience and said:

“In [neighbouring country] we took him to a special international
school which was by [western country]. But the teachers there were

locals. When he was there we often go to monitor, one day when we went there I saw another child was taught at a separate table, there it's all special needs children, and when he was not responding the teacher, to get the child's attention the teacher started pinching the child. The saw the teacher was pinching the child. When I saw this myself, I decided not to keep my child there anymore. So I discussed it with the school and took him back home that day itself. I did not believe that it will help by keeping there. When a teacher does that and if the school management cannot see that, then we didn't believe it's a right place for the child. The other day I had an advertisement on the paper to get a good teacher for home schooling ... [] ... Since then we had done home schooling for him".

(Xena, Clinic, 19/03/15)

This observation was noted in my field notes: "*As Xena was talking about the incident above, I could sense anger and hurt in her voice*" (interview and observation: 19/03/2015).

Yara also faced multiple challenges during the school years both at home and abroad. Although she was able to enrol her child in preschool in the home country, Yara's difficulties seems to have started from that early stage, first in the countries of origin. According to Yara:

"During preschool, we did have to face with issues related to school as she was a bit hyperactive. Especially the issues were around extra activities because she is not get readily included in somethings. Sometimes I feel that she was ignored as if she is not even a part of the class at times".

(Yara, Home, 05/04/15)

The first year of primary school was not any easier than preschool. Yara, as the mother seems to have faced emotional challenges to the point of having to literally 'beg' authorities in order to protect her child. Yara added:

"Then we moved on with her to the primary years ... [] ... we had to face some degree of bullying during the primary years ... During the first primary year, we did go to the education ministry, and we literally begged them to give my child a placement in a state school

where a cousin works. The reason we chose to do so was we believed that this cousin will be taking special care of her, related to her condition. With the blessing of Allah we did not have to face anything much that particular year”.

(Yara, Home, 05/04/15)

The second year of primary school seemed even worse as the challenges got worse as some teachers seem to be unable to handle and protect children with special needs in a mainstream class, which in Yara’s case was leading to further bullying of her child. She continued with sharing her experiences of her journey by saying:

“But the next year, though fortunately we had a good class teacher the difficult issues started coming up through some subject teachers ... hmm, [she mumbled to herself, this subject teacher and hmm] ...Ooh yeah, it was this one specific [named the subject] teacher. That particular teacher was teaching [named two subjects] these two subjects ... [] ... The oral test was given in the class in front of all the children. And my child made a mistake in pronunciation and everyone started laughing at her... [] ... Err this we requested because, when [child’s name] has to perform in front of people, she stammers ... [] ... many times it was always we having to ask for everything like this. It may be because [name of school] did not have trained teachers who know such conditions. They are trained for the mainstream. So I feel they are not unaware, um I mean they were not aware of such difficulties”.

(Yara, Home, 05/04/15)

An interesting finding, as can be seen above, is the mother’s acceptance, of the challenges the school is having too. After facing the challenges over the years in getting appropriate treatment and schooling, Yara finally reached a point, came to a realisation of having to look for services elsewhere in the world. But to her dismay schooling wasn’t an easy option abroad either. Initially, Yara was unable to get school placement for her child, hence, like Xena had to opt for home schooling until she gets a placement in a school. Yara explained:

“When we tried schooling, yeah was not easy. There too there were not many options when it came to education. There wasn’t much option at all. So in the very beginning, first we took her to a

specialised centre. We kept her there until she can be enrolled in a mainstream school. But also for one year we also did the home program, I mean we did home schooling ... [] ... We did this for about one and half years then we tried enrolling her in mainstream”.

(Yara, Home, 05/04/15)

A confounding factor, a not wanting to give up attitude seems to be apparent in the mothers’ journey. Yara, as a result, chooses to stay abroad and did all she could in order to provide her child with the best possible treatment and education. Aena also faced emotional challenges associated with the mainstream school. She talked about a severe incidence which happened and seemed to have shown her ability not to react to the incidence as it was emotionally tough for her. She said:

“In the concert one day, he pushed a child, and he was pushing the same child over and over again, suddenly among the audience someone behind me said, what a shameless child, like that. Suddenly I started crying because [child] is so little and even can’t talk well yet. So I decided I will never send [child] again and took him at once after they finished the concert”.

(Aena, Clinic, 17/03/15)

Zafa, who did not go abroad for treatment, also had her share of challenges in trying to find a school for her child within the home country. She like the other mothers seems to have done the best she could in facing every challenge that came her way. She said:

“First, we admitted him in (Preschool) and the teachers said he cannot hear. So then we had to enrol him in another school, in a particular class for hearing impaired ... [] ... But after a while, they said he does not have a hearing impairment. They said there was nothing that can be done for him in that class... []... So we kept him at home until we could enrol him elsewhere. We never gave up. ... []... Then we got a chance to (a state primary school) ... we took him to the school at 12:45, around 1:30 there was a call from the school to come for a meeting. I went to the school and they informed me, they cannot keep my child in school because he was running in class up and down, and the teacher was tired. It was a very sad day and I started crying. ... []... the principal also was there and she took

me to her cabin and advised me to admit him in (another state school) as they had special classes for children with disabilities”.

(Zafa, Clinic, 21/03/15)

Along with the challenges of providing their children with appropriate treatment, finding an appropriate means of schooling was neither easy. In addition to this, mothers also had to face numerous hurdles in other areas of life and the children’s development due to lack of awareness among their families and the wider society.

4.3.9 Further hurdles in the journey

Autism spectrum disorder as discussed in Chapter 1 and Chapter 2, is a condition in which impaired socialisation and impaired behaviour are among the major affected areas. Hence, part of the therapy involves helping autistic child to achieve normal socialisation and behavioural skills both within the home environment and the larger society. For this reason, mothers have to do certain things as part of the treatment program that they are following. This may include certain ways of working with the child within the home and even outside the home in the social settings. The lack of awareness among the extended family, close friends and the larger society became a hindrance to the mothers in working in these critical areas as required.

4.3.9.1 Challenges faced within family and close friends

The mother’s inability to freely work on these aspects of the children’s treatment seems to be related to the lack of awareness among significant others such as the extended family and close friends. Yara has faced such challenges within her home environment. Yara said this when talking about home environment:

“It was about the home environment. What I am saying is we were living on my [part of the significant family]. They are very good, very soft-hearted, very caring. But what happens is because of their

love I can't do as I should. I mean my child's behaviour is such that there are things I have to stop her from doing as part of therapy. But sometimes the [named some elders in the family] do things that that should not be done. When these things happen then what happens is later I have to face the difficulties when I have to work on her therapy goals, I find it difficult to modify her behaviour. I cannot get her to do things as I want and needed for her progress because she starts crying when I push to get things done. But her [elder of the family] cannot help herself and intervene as she finds it difficult to see her cry. So then during such times, my daughter gets her way and my ability to do what is needed for her does not get done".

(Yara, Home, 05/04/15)

The other difficulty Yara was facing was the inability to find enough time and the consistency she needed to be able to work with her child. Yara's challenges seem to be the result of having to live with the extended family that does not have the level of awareness and the understanding of the challenges of autism. Yara continued:

"The other difficulty having to live with an extended family was the inability to plan and stick to the schedule and give time to my child as required. I could not give as much time as needed, also because I was also working at that time ... [] ... mornings I go to work and then after coming back from work I had to help with regular house chores. If I couldn't help, hmm ... I mean if I couldn't then naturally family becomes unhappy, which results in small disputes, so sometimes I was forced to stop somethings I have to do for my child. So yes, actually due to working and also having to live with extended family, I could not give as much as I should have for my child".

(Yara, Clinic, 05/04/15)

Xena also voiced challenges she had to face within the closer home environment similar to the things that happened in the wider society, due to unawareness. In Xena's case, it was related to certain disturbing and inappropriate questions that came her way especially in the presence of her child both outside the home and within the home environment. According to Xena:

"Sometimes similar stuff happened within the family too, as we have two large extended families on both sides, those who were unaware of what is autism. Even non-family but close people, when we meet to ask questions".

(Xena, Clinic, 19/03/15)

In Zafa's case, unawareness led to rejection from extended family members.

According to Zafa:

“One day I was really disappointment in my home island. I visited my family on a holiday and one day we went to a sister's place and they did not allow my child to go into their house. They were scared that his condition may be contagious and their kids may be affected”.

(Zafa, Clinic, 21/03/15)

4.3.9.2 *Challenges faced within the society*

Similarly, mothers also found it challenging to help their autistic child with the social and behavioural issues outside the home environment which was also due to lack of awareness of autism and its characteristics among the wider society. Xena has faced such challenges and have said:

“When we lived here (home country) there were difficult moments, err as people were not much aware of autism at that time. Those days' people were really unaware compared to today ... [] ... I remember when we go out to places like the beach, he get a lot of attention, people will stop and stare at him, which we don't take wrongly because everyone can see the differences in him compared to normal children. I do understand they don't mean any harm; it's the lack of awareness among people. Because of this, we had great difficulty outside home ... [] ... These were very disturbing moments. Sometimes the questions were asked in the wrong way, for example, they ask things in front of [child]. We do feel sad although no one has directly been negative to him or us. We understood it was the unawareness. So we went through a lot while he was growing up. We had to go through a lot”.

(Xena, Clinic, 19/03/15)

Unawareness outside home environment was also experienced by Zafa.

According to her:

“When we go to the park too sometimes, he wishes to climb on and be on the seesaw, and because he is big, sometimes people will say “doesn't this boy know to give the chance to the kids?” Things like this happen outside the home. But I was not able to tell them that my

child is autistic and that's why he is doing so. If I ask my child to come to go home, he will make a big fuss and the onlookers will say things like "what a naughty child"... [] ... They see his age by looking at his height and they think he is a naughty and misbehaved child".

(Zafa, Clinic, 21/03/15)

Cefa also seems to have had to deal with stigma from the society which also was the result of unawareness in the society. Cefa explained about one such incidence she had to face. She said:

"The most difficulties we face when we go out with [child] [... ...] a bit far there was an old lady who said: "Is he a mad boy?" So I was very sad to hear that. I don't believe he is a mad boy so, after going home also I cried I didn't tell anybody".

(Cefa, Clinic, 17/03/15)

4.4 Phase 3: Maternal Metamorphosis

Phase Three of the journey for the mothers appears to be an intense life changing phase. The period in which the mothers having gone through the other two phases and the challenges and difficulties finally have come to accept the chronic nature of their children's condition. The phase that the mothers embrace as part of their 'being' and undergo a 'metamorphosis of self' to adapt and commit themselves to a never-ending journey. The many features of the phenomenological meaning, the 'essence' of raising autistic children are included in this phase of the lived experience.

4.4.1 Test of life – spirituality comes to rescue

One of the key questions asked to the participants during the interview was how they relate themselves to their journey of raising a child falling within autism spectrum disorder. How do they see the journey of having to raise their children with this lifelong

disability? The participants, the mothers of this research, seems to have embraced it as an examination, or in other words as their individual “Test of Life”. They believe it to be an unusual journey which they have not anticipated. Xena said:

“It's a very challenging journey, unexpected things happened. Nobody will expect for such things will happen in life. It was a big examination of life”.

(Xena, Clinic, 19/03/15)

For Xena, this test of her life has turned out to be the biggest challenge, test of her life.

The strength of spirituality, the role of belief, the faith and trust in Allah (God), seems to have been the means partly to overcome the intense sadness, the beginning of the acceptance and adjustments while facing the challenges of raising their autistic children. The pain and the fear of the past and the anticipated future were portrayed through the following communication between Yara and me. The final coming to grips and acceptance seems to have come out of ‘a spiritual being’ embracing ‘patience’ as the core in giving Yara, the ability to pick herself up and move on with her child.

“I: Okay ... okay now if you think of your life with your child, how would you describe it? I mean from the moment your daughter was born until this moment, what kind of journey is it for you?

I: [She froze] [Tears started pouring down] [She sat speechlessly] ... [Then slowly started melting down] [Sobbed] ... [Continued crying] ... [I got up and went to sit by her side] [Handed her some tissue and sat with her, my hand holding hers] [She took deep breaths in order to find grips with herself] [Was over one minute, but for me it felt like ages to see her go through the pain]

I: Okay, you okay now ...???

[She nodded, YES, seems like she finally got grips with her sadness, pain, etc. and started talking, very softly, slowly in a calm way]

Yara: Feelings eh, ... my feelings, it's a very unusual feeling, you have to be very patient ... need a lot of patience, without being patient you can't take care of a child like this. It's so many things ... [she went on to talk about all types of sacrifices she made combined with fear, and how she has embraced ‘a test of life to her life’]”.

Yara as well seems to have embraced her journey not just as hers only regarding a test of life but also a combination ‘test of their (she and her husband’s) life’. She continued:

“Honestly, I believe, my daughter, I mean we had her, to do things for her, I mean to do her things like this, I see it as a ‘test’ we have been tested on ... [] ... For us, the difficulties our daughter has, and our child having to face difficult challenges, having to go on such an extensive treatment, so I see it as ‘our test in life’. That’s how both me and [husband’s name] see this. So we believe we have to do it right, it’s a duty on us”.

(Yara, Home, 05/04/15)

For Yara, it appears as though that each person comes to this world with their test of their life. This feeling, the belief that each human is born with a specific ‘challenge’ ‘the test of their own life’ was further reinforced by Yara as she gave meaning to her journey of raising her autistic child:

“Yeah ... in other words, giving us a child like this ... I mean different people are ‘tested’ on different things in life. Each person is sent to this world with a set of ‘tests’ for each of them, with a certain set of responsibilities. Each person is ‘tested’ in a different way”.

(Yara, Home, 05/04/15)

According to Zafa, there are few important ingredients in the ability to be able to go on such a challenging journey of life. Zafa highlighted bravery and also patience like Yara as the core to be able to go on “*in this journey we have to be patient and brave. Otherwise, we can’t do it*”. Furthermore, Zafa also added the vital role of the individual’s belief in Allah (God) and the ability to embrace the challenges as their personal examination of life in their journey raising their autistic children. Hence, Zafa said:

“... [] ... also even without belief you can't do it. If you don't have a strong belief, you can't do it. I mean we have to believe, this is an exam for the last day. Otherwise, can't do it”.

(Zafa, Clinic, 21/03/15)

When people are faced with such difficult challenges of life, they attempt to do their best in doing what they were destined to do. The mothers have also found their distinct deeper meaning for their journey of raising their autistic children as part of their destiny. When one sees it as their test of life, the other seems to see it as a duty from Allah (God), their individual obligation of life. Zafa continued:

“Yes... Believing and accepting this is a part of my life. And also it's an obligation in Islam, like fasting and praying ... [] ... Yes, accepting is as an obligation. It is not an obligation but doing same as an obligation. Not only the mother but both father and mother have equally, otherwise you cannot”.

(Zafa, 21/03/15)

Cefa also said she too believes her journey of raising her child with autism is an examination of her life and her faith helps her to be strong. Cefa said:

“I would say this is an examination that I faced in life. We will go forward with it till we find a way ... I have a strong faith that keeps me strong”.

(Cefa, 17/03/15)

It was also found that the ability to move on with determination rather than feeling helpless also seems to be based on this strong belief and trust Allah (God). There seems to be no anger about their most important ‘test of life’ but instead, the mothers seem to have found themselves humbled, accepting and believing the idea of doing their best as they ought to just like any examination. It also appeared as though there was an inner sense of wanting a reward or some mothers had some level of fear of some misfortune if they fail in their life's exam. Zafa added:

Yes, as a must we have to do this task. Otherwise, you cannot go on smoothly, somewhere something wrong may go wrong.

(Zafa, 21/03/15)

4.4.2 Tenacity of love – determination to succeed

Love for their children coupled with persistence and determination seems to be an emotion that helps the mothers in doing what is best for the child. In the process, some mothers have been able to face the difficulties and challenges that came in the way between their children and their children's needs. According to Xena, this determination made her strong. She said:

“Umm, I mean I can't comment about my husband's feelings, but I can definitely say that I had not much concern about the fact that people look or say something. I have not worry about what others feel about my son. I didn't give much thought on that. Maybe it was because I was determined to give proper care and make my child ok that made me that strong”.

(Xena, Clinic, 19/03/15)

Zafa also seems to share similar feelings and have a 'never give up' attitude and went on to say:

“My aim was, I will never give up and will try as much as possible, prayed a lot, gave him 'Zamzam' (holy water) to drink and did 'sadaqah' (voluntary charity) by sending money to Mecca”.

(Zafa, Clinic, 21/03/15)

Zafa seems to have this strong never give up determination at every domain of the journey, whether it be schooling or with the therapies. She shared such feelings when she was talking about challenges of education. Zafa said: “... *I never gave up and admitted him to the special education class at (a state school)*”. She continued by saying:

“We went to get speech therapy but after a while the only speech therapist available then got sick and treatment got discontinued. So he was at home without any therapy as there are no other alternatives. We did work as best as we can as guided”.

(Zafa, Clinic, 21/03/15)

Zafa also have shown that her love for her child and the ‘never give up’ attitude gives her the strength to fight the negative pressures to the point of even facing life and death situation if she had to in order to protect and help her child. She talked through a painful incident that happened at a park one day and said:

“It was Eid holiday and [child] was very nicely dressed, I took [child] along with the other children to the park nearby. There [child] was waving hands like [child] always does. Sometime later I heard [child] calling mummy, and I saw that [child] was fully wet. [Child] pointed to a child there, and I asked him why did you do this? He said it is just for fun, because of [my child’s] behaviour. He is a very big boy [someone from the street gang], and what I did was, I went to the nearby shop and bought two bottles of water and came up to that boy, and I told him now I am going to make fun I will get you wet. He said if you did it would not be good for you. Suddenly I put the whole two bottles of cold water on that boy ... told them my child is not able to do anything to you, but I can. I said I’m not afraid of death; it will happen one day. So, I poured the water on them. The same day before we left the park, the same boy came to me and said, sister, I’m very sorry for what happened. So, you have to face with courage to what happens to the child”.

(Zafa, Clinic, 21/03/15)

4.4.3 Sacrificing of self – letting go of oneself for the other

The sacrifices the mothers have made for the sake of their children seem to be of many different types and levels. The desire of the mothers to live their children’s life appears to be an integral part of the mothers’ journey. The willingness to give up one’s aspirations in life such as giving up their jobs, livingness to live away from their husbands and loved ones, scarifying having a second child, giving extended hours to their children. In essence the mothers choose to give up on all other life priorities to live the life of their children.

According to Xena, she chooses to sacrifice her life of living with her husband and has stayed back in the home country rather than going and residing in a foreign country where her husband was studying because she did not want her child's language development to be effected in any way. She explained:

“We stayed in (a foreign country with a different language to the child's mother tongue) for one year and then came back to Male' on holiday. As my husband, has not completed his education he had to go but this time I decided to stay (home country), because of the weakness of my child's language development and we wanted to stay home so, we keep it to one language”.

(Xena, Clinic, 19/03/15)

Xena had not just once sacrificed her regular normal marital life for the sake of her child. When on another instant when she had to move to another country with her son in search of further treatment, she even went on that journey alone. Xena added:

“We went there (foreign country) and tried for about 1 ½ years. I was there with the two children alone and my husband was working back at home”. Moreover, she had also literally given up even having a second child for the sake of taking care of her autistic child during first few years, “actually we were hesitant to get a second child so we waited for 2 to 3 years and decided”.

(Xena, Clinic, 19/03/15)

Yara (a working mother) gave up her job and the career for the sake of facilitating the treatments needed for her child. In her case, the only possible choice she had then was to leave the home country and go and settled abroad where there was hope for her child. She said:

“I left as soon my bond was clear. As I said before, I have been wanting to go where I can get the services ... [] ... so, in fact, we broke the news to family only at the very last minute. Just within a month of breaking the news, I left abroad with [child]”.

(Yara, Home, 05/04/15)

Cefa also left her job and started staying at home to take care of her child with autism. She said: “... *but for the child, I’m staying at home*” (Cefa, Clinic, 17/03/15).

Like Xena, Yara also had to spend her entire marital life away from her husband in order to go and live abroad for the sake of the child’s treatment. “*As my husband couldn’t move with me, err, I mean, as my husband have to work to get money, and also couldn’t leave a good job, I had to go alone with [child]*” (Yara, 05/04/15). According to Yara, making the sacrifice was not a matter of choice, it’s a duty that she had to fulfil well, and she believes it’s a duty that both the mother and the father had to do. She went on to explain:

“Also, to do this right, to do our duty well, I mean to help our child to be able to live alone even if we are not there, to be able to live in the society, to do all this, we have to make several sacrifices. It’s like we can’t say, I can’t say I can’t do it, my husband can’t also say he can’t do it and if we stayed where we were without trying to get her the help needed, then it couldn’t have been this good. We made all these sacrifices and came all the way because we want our child to get better”.

(Yara, Home, 05/04/16)

Yara has explained the extent of sacrifices she as a mother has made but at the same time have given a fair share of credit to the father as well in the way of supporting her decision and the reason behind her success with her autistic child. She went on to say:

“We made lots of sacrifices. First, it was we had to live separately, that was the biggest sacrifice. And then the fear of anything going wrong between us, that was also a sacrifice we made, also for me having to live completely away from my own family, also in other words away from both families, then away from all my friends, more than friends it was family, having to leave my own country. ... [] ... So I had to make a lot of sacrifices. We couldn’t have succeeded without having made all the sacrifices”.

(Yara, Home, 05/04/15)

She further went on to explain that it's a no win situation to get out of it with success without making sacrifices because one way or the other its ends up sacrificing something or other in the process. She continued:

“Maybe yes, people who are very rich, maybe both husband and wife could have moved together. Even then all the other family sacrifices will happen. So any couple for that matter when they have to move, depending on their situation, it will always include some amount of sacrifices. If not it's not possible. If not you cannot manage something like this. It's like when you want one thing but to get that you have to sacrifice another. So if we want our child to get better, then we have to make the sacrifices. So, me and my [husband] sacrificed a lot to get here”.

(Yara, Home, 05/04/15)

As Yara continued to tell her story, the sacrifices she (they) had to make, it also was not free from the fear of realistic consequences of her situation, of their situation. She went on to explain:

“... []... for example away from the husband, alone, [still kept holding up tears and tried to continue and did] you know naturally will have some kind of family issues, for example the trust you have for each other, because we are living apart, both our needs, a lot of this, has to make so many different sacrifices [she cried a bit again and continued], alone, when you have to stay alone, [kept crying in between and talked through] I had to live alone circumstances made me alone, though I was married ... it was a blessing that I was blessed with such a good husband, fortunately up till now, as you know any couple will have issues, but these, the eight long years we have lived abroad, no real issue, I mean no such issue has happened that may lead to a divorce. I mean we both have been good and have not had any extramarital relationship or any such thing like that. Fortunately, nothing of those sorts has happened. The biggest, I mean one of the biggest things we both would be worrying is such extra marital affair or something, that is, I mean one thing, anyone would be worrying about this kind of life arrangements. That is one specific thing we think ... any couple will worry about”.

(Yara, Home, 05/04/15)

“I: You mean you had some degree of fear for that?

Yara: Yeah was scared of losing my husband, and him losing his wife. Or maybe the caring may stop, these are things anyone will worry right? But with the blessing of Allah nothing of that sorts have happened to us”.

(I (interviewer) & Yara, Home, 05/04/15)

The interesting finding here is that she has taken the decisions and seems to be well aware of the possible repercussions and has a degree of pain and sadness. *“I could see and feel intense pain through her nonverbal gestures, crying as she told her story. She seemed to be sad for how her life has turned out to be. At the same time, I feel comfortable and am confident enough to say that she had no signs of anger at any level about how her life has turned out to be with her autistic child. I was truly humbled and kept reflecting as a mother myself. I felt she had a sense of control of her life and inner peace in her, for having done her duty well”* (interview and observation: Yara’s Home, 05/04/2015).

Just like Xena, Yara also had sacrificed having a second child until she was sure her first child; her autistic child is independent enough to a level that they felt comfortable. Yara said:

“As our first child had all these difficulties, we waited a long time before we had our second child. Then before we planned for having the second child, we asked two different people for advice ... [] ... After that, me and my [husband] had a good talk and decided at that moment we will not yet have another child. We decided. First, we will make sure [name of child] is independent enough, reach a level we are comfortable, then only we will try for another child. So, then we waited. We got our second child something like about two years after we decided to have a child”.

(Yara, Home, 05/04/15)

But in Zafa's case no such issue was raised possibly because her child was not the eldest child in the family and she seems to have not thought in those lines. Cefa and Aena still have only one child, their autistic child. In Bera's case, her autistic child happens to be the youngest of her children.

4.4.4 Importance of significant others – part of the support system

Significant others such as the husbands, family, friends and even people like the landlord or the neighbour seem to be part of the support system that gives the mother extra help to carry on with the difficult challenges of raising their autistic child. The support came as either getting a direct assistance in taking care of the children or in the form of understanding the mothers receive from those the significant others.

4.4.4.1 Support from the husband and immediate family

When facing the difficulties of raising a child with autism, one of the paramount things is the acceptance and support of their husbands and significant immediate family members who are part of the mothers and their children's daily life. According to Yara, one of the most important aspects of the support for her came from the husband and the immediate family's acceptance of the child's condition.

“We then went home and discussed with our families as well. They also accepted. The happiest part for me was that [my husband] had accepted it. That was what made me most happy. At times when [husbands] don't accept these things, when things like these happen it's difficult, but I found it lucky that my husband had accepted it easily. That made me very happy”.

(Yara, Home, 05/04/15)

Yara also talked about the support she received from her husband and her immediate family as means of giving herself some personal time. She added:

“As I said as I was working and then ... I get just weekend to stay at home. On Fridays, my husband will take [child] for a ride. The only day I get to take her out was just the Saturdays, those days, the days I could go out, I try to take her to my family, I go to my own family ... [] ... and they were very supportive. I sometimes drop [child] there and go out and they will take care of [child] and monitor as well”.

(Yara, Home, 05/04/15)

Zafa also has shared similar feelings of how important it was to have the father to help her with daily chores of life and as well taking responsibility of working on certain difficult areas of the child’s development. As Zafa explained:

“Then my child’s father, he has played a major role in helping (child), like taking [child] to (nearby island) every day, daily 3 hours he takes the child for outing to give [child] freedom to run up and down, do whatever [child] wants to do. Sometimes in the park near the sea there is a small path, he takes the child there and leaves [child] to observe to see what [child] does. Now we have confidence that [child] will not jump into the sea. [Child] has improved a lot now. This was the father’s hard work, before [child] wasn’t aware of the surroundings and wouldn’t know what to do. Actually, this type of kids needs help from both parents”.

(Zafa, Clinic, 21/03/15)

Yara also highlighted the importance of an equal and an important role of the husband in the process of treatment and facing the challenges of raising her child.

According to Yara:

“In reality, the input of both of us is equal to get to the point we are today. Physically I am doing everything that has to be done. Financially everything is done by my [husband]. Because if [husband] does not support me financially, even if I am ready to physically do all the work, I could not have done this. I run here, and I run there to get things done. Without doing that I could not have got my [child] what was needed. Similarly, if [husband] sends me umpteen amount of money, if I don’t take [child] to the places I have to then [child] could not get the treatment needed. So it’s financial

and physical, and both have to do a fifty-fifty contribution for our child to get this well. That's how [child] is getting better with the grace of Allah”.

(Yara, Home, 05/04/15)

4.4.4.2 Support from significant others

The support of significant others such as the extended family, close friends or neighbours/landlords whom you and your child come in contact on a regular basis also seems to be part of the support system for the mother. For example in Xena's case, with her decision to stay home with the family for the language-related reasons, she seems to have felt the comfort and the support by the family's attitude towards her child.

“I thought if we were to stay in one place, especially staying with extended family, his vocabulary might increase by interacting with other children and family members. Because abroad we always have to live alone ... [] ... And the relationship with family members like cousins and aunts were very good as well. He enjoys playing with them ... We were living with our extended family. We found that they do give him more attention and caring about the diagnosis”.

(Xena, Clinic, 19/03/15)

Similarly, the acceptance and understanding of the child's condition and the difficulties by close friends have been a significant support for Yara, she said:

“So in a way really, not many of my friends has seen or met [child]. The friends who know [child] are really the closest few friends. Fortunately, when I tell them the problems, yes they do understand. They accepted, and they were very understanding and supportive”.

(Yara, Home, 05/04/15)

As for Zafa, raising her child with so many behavioural difficulties was eased and supported by the landlord's acceptance and attitude towards the child and her situation. She went on to say:

“The owner of the house is very good. They have helped us a lot. We are in that house with such a sick child for a long time; it’s because of the owner’s kindness. My child will throw things from the upstairs onto the ground, but the owner will never say anything. Sometimes the child will be lying on the stairs refusing to go up. It sometimes takes a long time to get my child up the stairs to our floor. But they never said anything to the child. Otherwise, we have moved here and there. With such children, nobody will accept. Shouting, banging, damaging things, nobody will keep such children, but this owner has never said anything.”

(Zafa, Clinic, 21/03/15)

Aena also has had understanding and support from family. She said “*also we have noticed both our families understand well. Everybody understand our child is abnormal, and especially my sister-in-law with whom I share everything, and she helps me, advise me in everything like small problems*” (Aena, Clinic, 17/03/15). Cefa’s family have also been supportive “*... my family supported me from the very beginning, and they wanted to keep us in [city] for the treatment even on their expenses*” (Cefa, Clinic, 17/03/15). Similarly, Bera also seems to have been supported by her family, “*at home, everybody knows so they take care while they are speaking to [child]*” (Bera, Clinic, 21/03/15).

4.5 Phase 4: The Transformed Self: A Journey through Hope, Towards ‘Hope’

A special place, which I have chosen to call as ‘hope’, a place where mothers can give the best for their children, seems to be the ultimate place the mothers aspire to reach with their autistic children. Mothers no more seem to challenge the standard norms of child development, but rather have learned to embrace and rejoice the small but significant changes in their children. They show a complete acceptance of their autistic children and their developmental differences. This change seems to be the result of the mother's strong spiritual belief in Allah (God), woven with the help of the intense love

the mothers have for their children, which in turn had given them a profound ability to sacrifice their selves and personal desires of their life for their children. It also seems to be supported externally by some support from the significant others as well. All the processes mentioned above have facilitated the phenomenological process of what I have called as ‘maternal metamorphoses’, Phase three of the journey, to enable the change, a transformed self, a new mother.

The journey towards ‘hope’ seems to be further facilitated by the slow but the step by step achievements the mothers have witnessed in their children. The ability to fly through the turbulences of their journey seems to have become the mothers’ second nature, their new life ‘the transformed self’. From this point of the journey, mothers appear to have achieved calmness and happiness, is very much in control of their journey, by embracing its share triumphs as well as the challenges, a transformed being living for the betterment of their children. Xena talked about her successes and future hopes of her child:

“First, when we started speech therapy, he was using single words and some two words phrases, but later he went on to making three and four-word phrases too. So it was the first improvement he had, this was a big relief to the child as he was able to say what he wants and also understand what others say.

The happiest thing was when we went and showed then, err the specialist said that though he has not received much specialist treatment over the years, they said he had been cared for very well and because of that he had improved and had not got any worse over the years. Their comments made me very happy. [Clinic] is well-reputed place there, so we were very satisfied with their comments. It was a great satisfaction for me. Then err ... then the other satisfaction for me is that I have brought him to this point today, up to the level he is today”.

(Xena, Clinic, 19/03/15)

As the years went by, the little but significant achievements seem to be what helps the mothers to keep going towards a goal, a place in their journey that their

children progress and achieve the best they can. Xena's journey continues with more triumphs, and she says:

“But meanwhile, something important has happened ... It was a very good chance, an opportunity [child] got from [a local college] ... It was a chance to do [area of study] ... and we also have thought and always realised it will be much better for [child] to study in this area ... [] ... We have always thought and considered for [child] to go with the easiest field for [child]. Something that [child] can use later ... So as [child] is an autistic child, we thought. As this field doesn't need [child] to communicate much with others. So that will be a great advantage ... [] ... I have talked to the teachers; teachers say that they have noticed [child] having fun with other students after the class. They have seen that. But still I think I have a lot of things to do for [child], and this journey is not yet over ... I am very happy that I achieved at least this much, but still want to do more”.

(Xena, Clinic, 19/03/15)

Yara too has her aspiration for her child as the journey moves on with the determination to get to the goal she wants to be with her child. In her case therapies has given her immense hope and happiness. Yara said:

“The most effective thing was therapy. Truly therapies ... Very successful. Fortunately very successful, but everything has, everything have a weakness, loops right? Weak areas will be there. Somethings that are dissatisfying will be there, but in reality, saying 90% was successful will be not a lie”.

(Yara, Home, 05/04/15)

Yara seems happy with her child's progress, her faith, her trust and belief in the goodness of Allah (God) in her journey seems to have got stronger with the slow but consistent success she sees in her child. She added:

“... [] ... after trying, we finally found about two schools which accept that. We enrolled [child] in one of the two we found. It's now been four years [child] has been in that school. [Child] is still there. With the blessing of Allah, it's been good”.

(Yara, Home, 05/04/15)

Zafa also after years of struggle seems to be enjoying the success of her child in an area he is capable of. Zafa's journey also appears to continue with a goal she has for her child. She affirms herself through her journey and added:

“[Child] has by hearted two chapters from the Quran and can easily read the whole Quran on [child] own. [Child] knows how to pray and has learned everything [child] need to for praying. [Child] does prayer call very nicely and my aim is to make [child] as an Imam”

(Zafa, Clinic, 21/03/15)

4.6 Conclusion

As can be seen above from the analysis of the mothers' lived experience of raising their children with autism, it seems to be a never-ending, lengthy, and challenging journey; a journey that the mothers have not anticipated in their life. But a journey, when faced with, had given them the strength even to change themselves for the sake of their children. Table 5.1: Stages and Phenomenological Meanings (supra page 126). The 'essence', the phenomenological meaning of their lived experience seems to be the mothers' exceptional ability to go through a process of 'maternal Metamorphoses' in their journey with their autistic children. The interpretation of the phenomenological meaning of the mothers' experience will be discussed in Chapter 5. Furthermore, I will shed light on these implications using some theoretical perspectives that I have found to be relevant.

CHAPTER 5 : DISCUSSION

5.1 Introduction

This chapter review and discuss the major findings of this study by relating them to relevant literature, including appropriate theoretical perspectives. The researcher will begin the chapter by briefly summarising the main results discussed in Chapter Four. Furthermore, the researcher will end the chapter with some implications that were highlighted by this research.

The study revealed that the mothers' experience of raising children with autism is a journey that could be conceived into four distinct, but interconnected stages. Stage One is characterised by the mothers' attempt to find a diagnosis that begins with an intuitive or innate ability to sense the autistic characteristics of their children. This stage has been described in the previous chapter with the associated challenges and emotions. Stage Two is a process of facing and overcoming challenges that I have grouped to four subheadings; confronted with the diagnosis, seeking treatment, challenges of schooling and further hurdles. These problems and difficulties have been explored in detail in the previous chapter. Stage Three is a stage in which the mothers go through an intensely emotional and profound experience of raising an autistic child which results in a deep depression and goes through a process which the researcher has termed as the maternal metamorphosis. Finally, Stage four is a phase, the mothers finally accept their children's condition and had transformed themselves, their identity, beliefs and dreams to empathise deeply and live for the needs of their autistic children.

This chapter is structured according to the four stages mentioned above. Under each stage, the researcher has discussed the key findings of relevant literature. She

also explored each result in connection with theoretical perspectives that may explain the results and offered her interpretive stance on the findings.

5.2 The Phenomenological Experience of Mothers with Children with Autism: A Journey

As mentioned above, the phenomenological experience of the mothers emerged as a journey consisting of four distinct but interconnected stages. It is a journey with a beginning and an end that leads to a form of a metamorphosis of the mother. This metamorphosis is the result of the process of raising their autistic children which are profoundly challenging with several types of hurdles that the mothers had to overcome.

The experience of mothers with autism has been characterised as a similar journey by other researchers. Jardine (2008), in her study that focused on the experience of parents (mothers and fathers) of raising children with autism, claimed that "...the idea of autism being experienced as a journey featured strongly across participants' stories and was reflected in the structure of their narratives" (p. 64). She depicted her participants' journey consisting of five critical stages reflected by the following themes: making sense of symptoms, what diagnosis means, acceptance and adjustment, reflecting on progress and the future.

Mann (2013) conducted a study on the experience of Jamaican mothers by conceptualising the experience of mothers as a journey from the onset of her study. The results of her study were not presented in stages of the journey, but she reported several themes that relate closely to the progression of a journey from beginning to the

end of raising a child with autism. These themes included the onset of birth, the period of diagnosis, the period of intervention and the future.

While the findings of this study complement the findings of others in this regard, it also adds more in explaining the journey by further exploring the final stage which the researcher has termed it as the stage of the transformed self which happened through the process of maternal metamorphosis.

5.2.1 Stage 1: A process of maternal intuitive diagnosis

Stage one of the journey includes two main findings which are discussed under two separate headings below. The first one is sensing differences in children and leading to an intuitive maternal diagnosis of their autistic children. The second one is the experience of obtaining a diagnosis is enduring and challenging.

5.2.1.1 Sensing differences in children and leading to an intuitive maternal diagnosis of autistic children

The phenomenological meaning of the mother's experience in Stage One is formed by mothers' natural instinct to recognise individual differences in their children when compared to other kids. This seeing of such differences begin at a very early stage of child development, and this study has revealed that mothers' have an inherent interest and an intuitive ability to capture subtle communicative and behavioural differences in their children. It is the mother's persistence concern, arising from observing such differences, that eventually helps them to secure the diagnosis. This can be interpreted as a form of maternal diagnosing combined with motherly instinct and driven by love of the child which eventually leads to obtaining a diagnosis.

This intuitive diagnosing of autistic children by their mothers has been reported by other researchers in various settings. For example, Jardine (2008), who explored into the meaning parents have in raising children with autism in the United Kingdom found that parents sensed differences in their autistic children, before obtaining a formal diagnosis.

Matenge (2012) conducted a study of South African mothers and had reported that mothers in her study being aware of their children's developmental deviances were prior diagnosing children as autistic. In offering an explanation for this phenomenon, Matenge (2012) relied on the work of Ahern (2000) who notes that "...parents often become concerned with their children's development months before professionals become aware of the signs and before a diagnosis of autism is made. Participants reported speech, language, pointing and awareness, rituals, eye contact and behaviour problems as early areas of concern." (Matenge, 2012, p. 12).

From the researcher, this phenomenon of maternal diagnostic instinct has significant implications for practitioners who treat autistic children, such as paediatricians, speech pathologists and therapists, child psychologists, occupational therapists and teachers. Such implications are explored later in this chapter.

5.2.1.2 The experience of obtaining a diagnosis is enduring and challenging

The second finding of Stage One is that getting a diagnosis is an enduring and challenging process. This prolonged and permanent nature of the diagnosis process has been reported by other researchers. According to Jardine (2008), the parents of her study have said that process of getting an appropriate diagnosis was not an easy process. Jardine said, "This search for an explanation indicated that there was often a

protracted period of assessment until autism was finally diagnosed” (Jardine, 2008, p. 66). Linn Hamilton’s book ‘Facing Autism’ (2000) written by a mother of a child raising autism talks about the persistent journey she had to go through in diagnosing her son with autism. Another book by Dillion (1995) was written based on the experience of six parents “Living with Autism: The parent's stories” also talks about numerous difficulties of having their children diagnosed.

In the researcher's opinion, while the phenomenological meaning of obtaining a diagnosis is found in persistently trying for a diagnosis with patience, the impetus to move ahead through this enduring experience comes from the depth of maternal love and concern for their children. The depth of love and care could be arising out of the maternal attachment which will be discussed below under theoretical underpinnings (supra pages 127-128).

5.2.2 Stage 2: The uphill battle

Stage Two of the mothers’ journey begins with obtaining the diagnosis of autism for their children. This phase consisted of having to absorb the news of the diagnosis and facing the challenges of getting therapy and schooling. In this stage, mothers also had to endure societal challenges related to social stigma. Managing one’s family affairs also presented several challenges. Discussed below are the experiences and emotions of the mothers, leading to what it means for them to raise their autistic children during this stage of the journey.

5.2.2.1 *Coping with diagnosis*

The news of one’s child being autistic unleashed a set of ‘inner’ struggles within oneself; these efforts inherently formed the meaning of the experience at this turning-

point of the journey. Mothers' initial reaction to their children's diagnosis of autism meant having to experience mixed and deep emotions, consisting of shock (disbelief and denial) and sadness. Among this set of mixed emotions, the most dominant were sadness. However, one among six participants, this shock was initially combined with a sense of relief since she had endured a long period of anticipating a diagnosis with a certain level of anxiety. Hence, in her case, obtaining the diagnosis for her child was an initial relief that too turned into sadness.

Other researchers have also reported similar emotions and meanings experienced by mothers of autistic children after receiving the autistic diagnosis. Bateman (2011) who conducted a study on maternal subjectivity in raising children with autism reported her participants as having profound sadness as the defining emotion immediately after getting the diagnosis.

Mann (2013) who conducted a similar study on Jamaican mothers also reported that the most prominent emotion experienced by the majority of the mothers immediately after receiving their children's diagnosis were feelings of despair and sadness. Bateman (2011) further reported that this grief soon channelled into a refocused effort of seeking the appropriate treatment for their children. Similar to the findings of this current study, Bateman (2011) also discussed some mothers who had a sense of relief immediately after receiving their children's autism diagnosis, which quickly turned into sadness.

A sense of relief upon receiving the diagnosis was also reported by some mothers of the above mentioned Jamaican study, in which the diagnosis became an answer they were seeking for their children's condition (Mann, 2013). Similarly, a study undertaken by Matenge (2012) on the experiences of South African mothers in

raising children with autism has also reported participants experiencing a sense of relief on receiving the diagnosis, which later turned into grief and sadness as the mothers realised the life-long nature of autism.

5.2.2.2 Obtaining treatment, sending to school, and adapting to social life

Inevitable external encounters related to therapy, schooling and adapting to social life gave rise to profound frustrations along the way. Mothers began external encounters while still holding the inner feelings of sadness in response to the initial diagnosis of autism. One key reason for this frustration was due to lack of appropriate treatment and schooling for autistic children in the context of Maldives. Also, mothers encountered a feeling of isolation by having to face other challenges such as social stigma, arising from lack of awareness of autism amid the extended family and the larger society. The overriding emotion at this stage for the mothers was deep frustration accompanied by sadness.

The research literature on mothers of autistic children points to emotions that are similar to “frustration” that arises from exogenous challenges. In referring to the participants of her study, Bateman (2011) said that “each barrier in the treatment and service-seeking journey invoked despondency, isolation and desperation” (p. 78). Similarly, Jardine’s (2008) study has also reported isolation as a result of lack of understanding from others. A study conducted in South Africa by Matenge (2012) discussed the participants of her study (mothers) were becoming angry towards their autistic children and other significant family members due to the challenges the mothers had to encounter.

5.2.3 Stage 3: The maternal metamorphosis

The initial shock of the diagnosis, as discussed in Stage Two, quickly led mothers to focus their attention on seeking treatment and schooling for their children. At Stage Two, the mothers accepted the autism diagnosis of their children without knowing its long-term consequences. A mother's acceptance of diagnosis appears to be a means to an end; it had become a necessary condition (i.e., acceptance of diagnosis) on the road for the mother towards getting help for their children. Towards the end of Stage Two, the mother had finally to face the permanency of autism and its life-long consequences, both for the mother and the child. This reality reshaped the mother's worldview on autism. It also challenged her to re-conceptualize her role as a mother. And, she had to re-adjust her own social and professional self with this realisation of the permanency and consequences of autism. This reassessment of oneself, one's place in the world, and one's professional and social roles carried the mother into the next stage, Stage Three, of their journey. Discussed below are the ingredients/factors that contributed to a mother's transition from Stage Three to Stage Four; this transition is also a transformation of self.

5.2.3.1 Spiritually comes to the rescue

The shocking and the challenging moment of realising the life-long nature of the children's condition threw the mothers into a deep state of sadness. The mother could not remain in this deep state of grief for long, as it would have meant leaving her vulnerable child alone to survive in the world – a world full of challenges that the mother has bargained for years in trying to raise her autistic child. At this delicate moment, what came to each mother's rescue was their spirituality, the faith they have in Allah (God). This faith in God consisted of trust in God, accepting their destiny as the will of God, and having the spiritual patience to endure the challenges of raising

their autistic children. For example, Yara said: “Feelings eh, ... my feelings, it’s a very unusual feeling, you have to be very patient ... need a lot of patience, without being patient you can’t take care of a child like this” (Yara, Home, 05/04/15).

The faith also consisted of a strong belief that in their fate of having to raise a child with autism as a “test of life”. Yara has said: “for us, the difficulties our daughter has, and our child having to face difficult challenges, having to go on such an extensive treatment, so I see it as ‘our test in life’” (Yara, Home, 05/04/15). Xena echoed similar emotion: “it was a big examination of life’ (Xena, Clinic, 19/03/15).

The fear of the consequences of failing to perform a God-given duty also played a role in the acceptance of committing oneself to raise their autistic child to the best of one’s ability. Zafa self-proclaimed: “Yes, as a must we have to do this task. Otherwise, you cannot go on smoothly, somewhere something wrong may go wrong” (Zafa, Home, 21/03/15).

The role of spirituality has been discussed by other researchers as well. Heydari, Hosseini and Mohammadpour (2015) conducted a study on Muslim Iranian mothers raising children with autism have reported spirituality as the central theme. In this Iranian study, some of the mothers have also accepted raising an autistic child as their destiny, duty, a ‘test of their life’. Heydari et al., (2015) concluded saying that “caring for the autistic children led mothers’ lives to raise spirituality and enabled them to help their children and themselves, to grow and be refined in this process” (p. 79).

The study by Bateman (2011) has also discussed the mothers’ belief that the reason for certain things to happen the way it does has a purpose in their life hence

accepted raising their autistic children as their fate or destiny. Batman quoted one of her mother's, Meredith who have said: "I've come to the conclusion that I was probably made for this journey and that it was my destiny . . ." (Bateman, 2011, p. 116).

5.2.3.2 Love gives way to sacrifice

True acceptance can only be achieved with a shifting of one's worldview to allow change of one's self. This level of willingness to change of one's self was a result of the mother's faith in combination with deep maternal love, which was driven by a strong determination to protect one's child. In this process mothers have to make several sacrifices of their self, allowing themselves to change for the well-being of their children.

Research on mothers raising children with autism has been shown that mothers make several adjustments and sacrifices in order to adapt to their child's needs. The ability to alter one's self for the mothers was helped through the spirituality (Heydari et al., 2015). Other studies have shown that maternal love and the desire to give the best for their children have enabled the mothers to make enormous changes to her life which involves various sacrifices.

The study done by Bateman (2011) reported that mothers in her study have moved their homes, changed their lifestyle, and even took major financial decisions such as taking a loan for the sake of the betterment of their autistic children. In essence, the mother's live their life from dawn to midnight with the child, for the child even if it meant it is taking a toll on their lives.

5.2.4 Stage 4: The transformed self – completion of the maternal metamorphosis

In Stage 4, the phenomenological meaning of the mothers' journey is woven with the characteristics of transforming themselves into unique human beings with several characteristics: spirituality, patience, calmness, hopefulness, realistic, humbleness, determination and protectiveness.

In this stage mothers changed into 'malleable beings' – people who can adapt all aspects of their lives views in response to the needs of their children. This malleability meant that the mothers would not hesitate to give up their dreams and careers for the sake of their children. It also suggested that mothers could let go of certain family members and friends, and accepting others, to suit the needs of their children. The significant others in their children's lives became mothers' friends. For example, therapists became mentors and friends, and effectively took on the role of family members. Other mothers with autistic children became mentors and friends too.

The mothers at this stage do have on and off sadness with the challenging milestones of the children, but at this juncture, the sadness is lighter, more wise and controlled. Mothers have become humble beings through the years of bargaining, soul searching, accepting and finally transforming into a unique 'malleable' being. The mother who have gone through a process of metamorphosis, resulted in a 'guardian angel' of their autistic children, on duty at all times, in all situation as required.

Others' research too have illuminated this aspect of transformation of self, change of world views in the process of facing and moving on with the challenges of raising their autistic children. One such study was done by Bateman (2011) "Living

Liminality” concluded that for the subjects involved in her study “the experience of living liminality facilitated the development of distinct orienting contexts for making meaning and navigating intrapersonal and interpersonal experiences that, in turn, manifested in a reappraisal and reconstruction of maternal subjectivity” (p. 119), as a result the change that occur within the primary caregivers as they adjust to life with their autistic children.

As a conclusion for this part, the researcher summarise the journey the mothers went through in Table 5.1.

Table 5.1: Stages and Phenomenological Meanings

Stage	Phenomenological meaning
Stage 1: The Maternal Intuitive Diagnosis	Begins to focus on the child’s communication and behaviour patterns Fearful and anxious to know what is wrong Seeking answers from others Intuitive knowing that the child is not normal, yet unable to identify and give a name to it
Stage 2: An Uphill Battle	Feeling of shock (disbelief, denial) Overwhelmed with sadness after getting the diagnosis Starts bargaining with the world around Experience frustrations with lack of help and not seeing progress as desired Facing isolation as a form of rejection due to unawareness of others
Stage 3: The Maternal Metamorphosis	Onset of depression with the realization of the life-long nature of autism Spirituality provides answers for questions within one’s self Deep maternal love, desire to protect one’s child, forging of one’s self for the sake of the child Moving towards acceptance
Stage 4: The Transformed Self	Embraced God’s will, complete ownership of child with autism as one’s destiny Calm and hopeful of the future with a realistic focus Strong and confident in facing the challenges A malleable being who can adapt to any situation for the child

5.3 Theoretical Perspectives on Mothers' Experience of Raising Children with Autism

The findings related to the four stages of the mothers' journey are discussed above in light of relevant literature. The researcher interpretations of these results, based on 25 years of her experience as a speech and language therapist for treating various speech and language disorders including autism, were also offered above. In light of these discussions, below is a conceptualization of the mother's journey supported by theoretical underpinnings. In doing so, the researcher has first developed a table to illustrate the stages of mother's journey in which she has summarised the key phenomenological meanings (the essence of the experience) under subsequent stages.

The researcher has also made use of four metaphors that denote the role that defines the 'inner experience' of the mothers during respective stages. These are (1) The Intuitive Diagnoser, (2) The Warrior, (3) the Soul Searcher, and finally (4) The Guardian Angel (See Table 5.2).

The researcher discusses the four stages of the mothers' journey she has just mentioned above using theoretical perspectives as indicated on Table 5.2. These include Winnicott's (1988) notion of mother-child attachment bond, the role of oxytocin in mother-child bonding by Gallbaly et al. (2001), Elizabeth Kubler-Ross's (1969) theory of grief and recovery (the grief cycle) and Mezirow's (1978) theory of transformative learning. First, the researcher introduces key aspects of the theoretical perspective before she explores the stages further in Table 5.2.

Table 5.2: Stages Representing Metaphors and Theoretical Underpinnings

Stages and Representing Metaphors	Theoretical Underpinnings
Stage 1: The Maternal Intuitive Diagnoser The Intuitive Diagnoser	Winnicott (1988) notion of a strong maternal attachment and an innate connection Notion of chemical/hormonal (Oxytocin) bonding of mother and child (Galbally, Lewis, IJzendoorn and Permezel, 2011)
Stage 2: An Uphill Battle The Warrior	Elizabeth Kubler-Ross (1969) theory of grief and recovery: The Grief Cycle - Stages 1 to 3 Mezirow's (1978) Ten Phases of Transformative Learning - Phases 1 to 7
Stage 3: The Maternal Metamorphosis The Soul Searcher	Elizabeth Kubler-Ross (1969) theory of grief and recovery: The Grief Cycle - Stage 4 Mezirow's (1978) Ten Phases of Transformative Learning - Phases 8 to 9
Stage 4: The Transformed Self The Guardian Angel	Elizabeth Kubler-Ross (1969) theory of grief and recovery: The Grief Cycle - Stage 5 Mezirow's (1978) Ten Phases of Transformative Learning - Phase 10

Winnicott's notion of 'good-enough mother' is based on an attachment bond that is developed between the mother and the child very early on in the child's life (Sharpe, 2012). According to Sharpe (2012), Winnicott (1988) also have stated that the mothers have an intuitive ability to know little things about their children even without any erudite knowledge. Illuminating on Donald Winnicott's notion of attachment of the relationship between the infant the primary carer (mother), Bunce & Rickards (2004) have said that "following birth, the 'good enough' primary carer becomes preoccupied with the welfare of the infant, a state known as 'Primary Preoccupation'" (p. 3). The researcher believes that this concept of the strong mother-infant attachment helps to explain the phenomenological meaning of mothers experience during the Stage 1 of the mother's journey (see below under Stage One, the intuitive diagnoser).

Oxytocin's role in infant-mother bonding is an area that is researched on. According to a review done by a group of researchers (i.e., mostly paediatricians such as Galbally, Lewis, IJendoorn and Permezel 2011) on the role of oxytocin in mother-infant relations concluded that high levels of oxytocin in the mother's blood at the time of the birth helps in forming a strong bond between the mother and the infant from birth. Hence, in the researcher's view oxytocin could be what enhances the deep attachment that mothers develop with their autistic children (see the discussion below under Stage 1, the intuitive diagnoser).

Elizabeth Kubler-Ross (1969) grief cycle is a theoretical perspective that explains the process of grieving when people are faced with death or loss of loved ones and explain the process that people go through a healing process when confronted with such events of life (Chapman, 2000-2013). Furthermore, it was noted that not everyone will go through all the stages the same way but more or less will. The grief cycle consists of denial, anger, bargaining, depression and acceptance, the five stages presented by Elizabeth Kubler-Ross (Chapman, 2000-2013). I will explain the five stages of the Kubler-Ross grief cycle as relevant to stages 2, 3 and 4 of this current study, the warrior, the soul searcher and the guardian angel respectively.

According to Mezirow's (1978), the theory of transformative learning provides ten phases. This theory of transformative learning challenges people when faced with a difficult life crisis. As stated by Hatherley (2011), Mezirow's transformative learning is not just about gaining knowledge, but it is also of making meaning and learning through critical self-reflection. As Kitchenham (2008) explained:

“...in short, the learner encounters a problem or anomaly that cannot be resolved through present meaning schemes or through learning new meaning schemes; the resolution comes through a redefinition of the problem. Transformation occurs by critical self-reflection of

the assumptions that supported the meaning scheme or perspective in use”

(p. 112).

The ten phases of Mezirow’s transformative learning are (Kitchenham, 2008):

- (i) Phase 1- a disorienting dilemma,
- (ii) Phase 2 - a self-examination with feelings of guilt or shame,
- (iii) Phase 3 - a critical assessment of epistemic, sociocultural, or psychic assumptions,
- (iv) Phase 4 - recognition that one’s discontent and the process of transformation are shared and that others have negotiated a similar change,
- (v) Phase 5 - exploration of options for new roles, relationships, and actions,
- (vi) Phase 6 - planning of a course of action,
- (vii) Phase 7 - acquisition of knowledge and skills for implementing one’s plans,
- (viii) Phase 8 - provisional trying of new roles,
- (ix) Phase 9 - building of competence and self-confidence in new roles and relationships; and,
- (x) Phase 10 - a reintegration into one’s life on the basis of conditions dictated by one’s perspective.

These ten phases when compared to the stages of mother’s journey discussed in this study, certain parallels can be observed. These parallels as relevant are discussed in detail below. The researcher believes that Mezirow’s theory of transformative learning provides an alternative and perhaps a more meaningful explanation of why the mothers’ journey is such a transformative process. Therefore,

she would also explore Stages 2, 3 and 4 in light the perspective of a learning experience with the help of Mezirow's theory.

5.3.1 Theoretical perspective on Stage 1: The Intuitive Diagnoser

Based on the experiences and meanings during stage 1 (see described above), the researcher has coined this phase and chosen a metaphor to capture the essence of the mother's experience in this stage as the 'intuitive diagnoser'. At this early stage, the mothers begin to see differences in their children even though the mothers wish their children to be developmentally normal. The more they keep seeing the differences in their children, both speech delay and the behavioural deviances; mothers come to an intuitive conclusion that their children have some problem though the mothers are unable to give it a name. As a result, the mothers seek professional help.

5.3.1.1 The notion of Donald Winnicott's attachment bond

From the opinion of the researcher, this phenomenon of mothers' sensing their children's developmental differences can be partly elucidated through the notion of Donald Winnicott's a 'good enough mother', a secure attachment bond formed between the mother and the infant. I believe the unique and strong nature of this attachment is perhaps what gives rise to mothers' intuitive ability and constant interest to see the indefinable yet 'unusual' characteristics in their children. This intuitiveness coupled with the mother-child attachment/bond possibly provides the mother with a unique pair of 'lens' through which they observe their children. As a result, the mothers detect the child's subtle nuances, the differences in their children, may it be delayed speech development or the deviances in the children's behaviour. The reason mothers get anxious and seek professional help.

5.3.1.2 The role of oxytocin in mother-child attachment

Another contributing notion that can illuminate additional light on an amazing mother to infant bond very early on is explained above, the role of oxytocin. Hence, once again the power of the mother to infant attachment bond which is formed through oxytocin, can be another influencing factor why the mothers observe subtle changes in their autistic children and sense the differences so early on before anyone else can do so.

As shown in the table above, the next three stages that follow can be best explicated through the five stages of grief as argued by Elizabeth Kubler-Ross (1969) and also with the help of ten phases of transformative learning theory by Mezirow (1978). While the participants of this study did not exactly progress through these five stages of Elizabeth Kubler-Ross grief cycle in the same order, there are some similarities with just one significant difference (supra pages 132-135). The researcher discusses the stages in relations to Kubler-Ross grief cycle as relevant under each heading. Similarly, she will also do the same concerning the ten phases of Mezirow's transformative learning theory (supra pages 132-135).

5.3.2 Theoretical perspective on Stage 2: The warrior

The mother's experiences and meanings during stage 2 (see described as above), is captured through the metaphor of 'the warrior'. The mothers at this stage had to fight an uphill battle – fighting with one's inner emotions, therapy, schools, and social settings.

5.3.2.1 Kubler-Ross grief cycle

Kubler-Ross's Grief Cycle consists of denial, anger, bargaining, depression, and acceptance. When one explores the warrior stage of the mothers' journey in light of

Kubler-Ross's Grief Cycle, several similarities can be observed. Mothers in this study did have the experience of shock, denial and disbelief, reflecting the first stage of the Grief Cycle. Denial of the mothers was followed by sadness instead of anger as in the Grief Cycle. In my opinion, anger in Grief cycle was replaced by sadness in the case of the mothers in the study is because of the socio-cultural setting of the study. Maldivian mothers have conceived having an autistic child as the "will of God" due to faith in Islam; it was perceived as fate. This aspect will be further discussed under the Guardian Angel Stage below.

With this sadness mothers began the process of battling and bargaining, making it difficult to separate the stage of grief with the stage of negotiation. Perhaps the reason for this merging of the two stages is because these mothers could not pause with sadness, they had no other choice but to carry the burden of grief into action – i.e., bargaining their way into the society with their autistic children for urgent treatment and education.

5.3.2.2 Mezirow's transformative learning

The warrior stage (Stage 2) can also be explained through Mezirow's theory of transformative learning. Mother's experience from this perspective is seen as a learning experience, resulting in the transformation of the self on facing the shocking news of their children having autism. From the above ten phases, phases 1 to 4 has a similarity to the stage that the mothers go through at the point of receiving the autism diagnosis. Mothers having faced with the condition that they did not foresee in their life, hence mothers went through a period of confronted with a big dilemma hence was forced to reflect on the challenges they are faced with. The following three phases i.e. phases 5 to 7 also has a similarity to the stage the mothers in this study went through.

That is exploring the option, planning actions and acquiring of knowledge and skills to take care of their autistic children.

5.3.3 Theoretical perspective on Stage 3: The Soul Searcher

The mothers' experiences and meanings during stage 3 are captured through another metaphor which is the 'soul searcher'. At the beginning of this juncture mothers initially went into a deep sadness with the realisation of the life-long nature of autism. At this critical point in which the mothers started searching for answers within one's self, what came to the mothers rescue was their spirituality followed by deep maternal love as a desire to protect their vulnerable children. As a result, they went through a transformation process of their self towards acceptance of their autistic child as an inseparable part of their being.

5.3.3.1 Kubler-Ross grief cycle

In this stage of the mothers' journey, they seem to go through another similar stage of Kubler-Ross grief cycle, the phase of depression, the stage where sadness finally challenges one through the process of beginning to accept reality, paving a way to the next stage, stage of acceptance. The mothers of this stage also went through a deep sense of sadness, searching through their deepest inner soul, and finally moving towards accepting their autistic children as their reality of life.

5.3.3.2 Mezirow's transformative learning

Mezirow's phases 8 and 9, the stages in which individuals go through a process of trying of new roles, building competence and self-confidence in finding new relationships can be related to the mothers' soul searching and coming to terms at this stage of the mothers' journey. That is before they could finally be able to move to the

final phase of the transformed self, a mother who have finally accepted and decided to live their new life as a new mother. Mezirow's phases 8 and 9, the stages in which individuals go through a process of trying of new roles, building competence and self-confidence in finding new relationships can be related to the mothers' soul searching and coming to terms at this stage of the mothers' journey. That is before they could finally be able to move to the final phase of the transformed self, a mother who have finally accepted and decided to live their new life as a new mother.

5.3.4 Theoretical perspective on Stage 4: The Guardian Angel

The mothers' experiences and meanings during stage 4 are once again seized through another metaphor which is the 'guardian angel'. By this stage, mothers have been able to accept their autistic children as God's will one's destiny. Mothers at this stage are calmer and hopeful with a practical focus, working towards their children's individual developmental goals. They are more stable and confident in facing the challenges. Last but not the least, the ultimate essence of this journey is the transformed new mother, a malleable being who can adapt to any situation for the sake of their autistic children.

5.3.4.1 Kubler-Ross grief cycle

In this stage of the mothers' journey, it appears to be similar to the final stage of Kubler-Ross grief cycle, the stage of acceptance. In the stage of acceptance similar to Kubler-Ross grief cycle, mothers had finally accepted the reality of the permanent nature of autism and their challenging life of raising their children. At this point, mothers have finally accepted, adjusted and start to move on.

5.3.4.2 *Mezirow's transformative learning*

The self-transformation that occurred in the process of raising an autistic child, in this final stage of the mothers' journey could be once again well explained through the Mezirow's theory of transformative learning. From this perspective, the experience of raising children with autism became a transformative learning experience in itself for the mothers. It was an experience that compelled them to reflect and assess many assumptions they had held about children, what it means to raise a child, family members and life in general.

Mezirow argues that certain types of experiences – ones that are emotionally charged and cognitively challenging have the impact on self that begins a process of deep self-reflection. Such experiences after having gone through the initial phases of questioning the pre-existing assumptions, having gone through the explorations of options and renegotiating and negotiating with the world, mothers finally were able to change the worldview of oneself. Hence they reached the final phase, Phase 10, in which the mothers reintegrate into the world with the new reality, as the newly transformed mother, the guardian angel.

5.4 Implications

There are several implications of this study. The consequences fall into three broad areas. Those are the implications for clinical practice (speech and language therapy), future research and contributions towards policies of the current setting, the Maldives and also for other similar settings that may share such a nature.

5.4.1 Clinical practice: speech and language therapy

The importance of this research for clinical practice serves in several ways. They are the contributions towards diagnosis, treatment and to other related professions.

5.4.1.1 Acknowledging mothers as an important part of the diagnosis process

Early identification is crucial for early intervention which the researcher believes is a process that should not be delayed to overcome challenges of autism. In almost all cases, appropriate diagnosis becomes the way forward towards appropriate early intervention. This study has clearly shown that the mothers are the first people who sense and identifies the differences and deviances in their children's development. Previous studies in other parts of the world have also highlighted related findings (Jardine, 2008; Matenge, 2012). To avoid loss of valuable time, the mother's concerns regarding their children, however, subtle it may be, should be valued as important markers and taken seriously by the professionals. This phenomenon of the mothers noticing such nuances in their children has been discussed above under the headings 'maternal intuitive diagnosis' and 'the intuitive diagnoser'.

5.4.1.2 Mother-Therapist model for supporting children with autism

This study's findings along with the researchers own clinical experience as a speech pathologist, and a therapist has more than ever reinforced for her to say that mother's role in treating children with autism should be given a lot more importance and weight. The researcher believes the need to embrace mothers as co-therapists in treating their children with autism, and what the researcher would like to name as 'mother-therapist model' in supporting children with autism. This model can also be valuable in treating any long-term childhood disability.

The reasons for such a consideration is, firstly, the study has clearly shown that the above mentioned, the initial ‘intuitive diagnoser’, the mothers are the first people who recognise the differences in their children, hence know their children’s differences, deviances and difficulties very well. Secondly, the mothers (main caregiver) are the people whom the child is most attached to, and in most cases, most time spends with as well. Hence involving mothers as co-partners in the treatment program will ensure that the children’s chosen goals will be worked on at least 6 to 8 hours a day. As a result, the benefit of such a joint program can be immense rather than the children only attending a session of an hour with the therapist twice or thrice a week. The involvement of the mothers will also mean that the family also will become more involved with the treatment goals as it’s continued at home by the mothers.

Furthermore, the religious and cultural beliefs of a given society and the parents who are in the process of having to raise a child with a long-term disability such as autism, need to be embraced by the professionals who are working with the parents. The clinicians have to adopt the parent’s state of mind and the processes that go through the acceptance process for valuable counselling of such parents. A crucial aspect of the therapeutic process for the child to get the most out the treatment, empowering and taking care of maternal or parental well-being.

Faith seems to play a vital role in the ability for parents in accepting their children with lifelong disabilities such as autism. Acceptance is one of the key ingredients for any individual to be able to cope with life’s hardships mentally. The role of spirituality and faith has been discussed by few other researchers from studies done on a Muslim population. One such study that has findings in harmony to this current research is a study done by Heydari, Hoesseini and Mohammadpour (2015) on

a group of Muslim Iranian mothers raising children. This particular study has reported the significant role of faith in Islam in acceptance of a lifelong disability such as autism.

Bayes (2015) paper on 'A Biblical View of Disability' under the sub-heading 'What Disability is Not', talks about seeing disability not as karma or a curse but rather in a more positive way. According to Bayes "affliction or disability is not hindrances to God's grace in our lives – quite the opposite" (para. 1-3). Sarris (2014) another paper on 'Autism and Faith: Inclusion and Acceptance at Places of Worship' under the heading 'Embraced by her Church, helping others with autism' talks about a mother's acceptance of her son with autism as God's grace, a gift from God and wanting other mothers to do the same.

Studies on different faith groups have been reported by other researchers and though there is a link to faith and disabilities in various religions, it does not necessarily come with a positive connotation. According to Moore (2015), attitudes towards disability in various religions such as Hinduism, Buddhism, Christianity and even Islam does have negative connotations and consequences attached to it. But there too Moore (2015) states that:

"Muslim apologists differ little from the apologists of other religions when it comes to defending contemptuous attitudes toward the disabled. Shaykh Abd al-Rahmaan al-Barraak, a Saudi scholar who recently issued a fatwa sanctioning the killing of advocates of gender mixing at work and in education, wrote an essay on why Allah created mental disabled people, a question that he answers as follows: "His perfect wisdom decrees that He creates opposites.... He created His slaves with differences in their bodies and minds, and in their strengths. He has made some rich and some poor, some healthy and some sickly, some wise and some foolish. By His wisdom, He tests them, and He tests some by means of others, to show who will be grateful and who will be ungrateful" (al-Barraak, n.d)"

(Para 23).

The above and what Moore (2105) states further is very similar to the voice of the participants of this current research. Moore (2015) further stated that: *“Wasif Islam offers a similar justification: “[B]eing disabled is a test from Allah in this life, and therefore can be a blessing in disguise. Every disabled person should be patient and live up to this challenge. Allah promised those who observe patience a great reward in the Hereafter” (Islam, 2009)”* (Para 24). The religious beliefs and attitudes need to be considered when treating and empowering parents with children with disabilities.

5.4.1.3 Social support programmes for mothers with autistic children

Having said the above, another important factor is that as this research have shown that mothers go through an intense emotional journey with several stages from the time they sense their children have a problem through into the final stage of acceptance. These stages as discussed above had deep emotions of varying types and degrees. Hence it is also vital that the clinicians can identify which stage the mothers are at a given moment, to understand the mothers’ psychological condition, the ability and the speed at which the mothers can cope with for the success treatment.

For this, a well-planned social security and support system is crucial. Parents need to be emotionally and financially supported as well as socially accepted. Autism being a disorder with many behavioural issues which as a result leads to social stigma, is an area a given society or nation need to work on. Past studies done by other researchers in different parts of the world have found it critical as well as part of supporting the family in the best possible way (Rahman, 2005; Woodgate, 2008; Mak and Kwok, 2010; Connolly, 2015). One way of overcoming challenges related to raising children with autism is providing psychological support for the families with children with disabilities (Barbosa, et al. 2008). This involves shifting attitudes at

societal level with public education and proper exposure and helping the families to adapt to their normal life (Midence and O’Niell, 1999; Beatson and Prelock, 2002; Mak and Kwok, 2010).

Mothers in particular and families in general need to be helped and guided and empowered at their individual pace for them to be able to do the best for their children in such a life-long enduring journey. This would then become a more realistic, sustainable and beneficial model of treatment for the children and their families.

5.4.1.4 Multidisciplinary Remedies

The next important implication of this research is for the other clinicians of the multidisciplinary team. As autism is a disorder with three core areas of impairment, namely social, communication and behavioural, a multidisciplinary team comes into contact with the children and their mothers in the treatment process. Hence related professionals who work with the children and mothers (main caregivers) such as medical practitioners, clinical psychologists, occupational therapists, physical therapists, teachers and social workers might want to consider the factors mentioned above in their respective treatment process.

A holistic treatment model that addresses and relates to the mothers and the children can have positive implications for successful treatment.

5.4.2 Research implication

This current study’s findings have also highlighted two different areas of research to support and enhance the meaning of this current research. Firstly, as fathers’ role, though different, have been emphasised in this research. Hence doing similar research

on fathers of autistic children can contribute to new meaning to the holistic care of children with autism. Secondly, with the life-long and challenging nature of autism, another important population the research can add more meaning can be the integrated family including the siblings and significant others of children with autism.

5.4.3 Policy implication

Social policies for any given country are of the essence when dealing with minority and vulnerable groups of the population. This study as mentioned above have also identified areas that the policy makers need to address especially in such small and less developed countries such as the Maldives, the setting of this study. Given the fact with the level of increase of autism in the country, the policies need to be made in such a way that the social care is inclusive of not only the children but also their caregivers as well. Hence the following need to be taken into account.

Firstly, the service and training requirements have to be evaluated and addressed because lack of professionals and inability to get early intervention leads to loss of valuable time for the children with autism.

Secondly, as autism is a life-long disability it has a significant impact on the families both emotionally and financially. Hence, support services need to consider and address these two paramount areas to help the families so that they can help their children's in the best possible way. The emotional and social aspect has to consider the individual differences as well as cultural differences in the country. According to a study done by Lin L-Y, et al. (2010) suggested that cultural differences can have implications in the ways of coping among different cultures. Hence, public awareness on autism needs to be sensitively and sensibly aimed at especially in such small

communities incorporating cultural norms and beliefs to meaningfully help the children and the families of autism.

Last but not the least, policy makers need to embrace mothers / parents of children with autism as important stakeholders of autism and other long-term disabilities while policies are formulated. If not the policies would lack the necessary meaningful ingredients needed to face the challenges of raising children with autism.

CHAPTER 6 : CONCLUSION

Autism is lifelong developmental disorder. The role of the main caregiver (in general the mother) is critical in the treatment process. The aim of the study was to explore the life experiences of Maldivian mothers raising children with autism and the meaning they ascribe to their journey.

The methodology used was an interpretative phenomenological analysis of the Maldivian mother's experience in raising their children with autism. A purposive sample was selected among Maldivian mothers who have been raising children diagnosed with autism. The mothers selected were those who have at some point in their children's life been in contact with the speech pathologist and therapist, the researcher. The aim of the study was achieved by conducting in-depth interviews with six mothers from the Maldives with autistic children. The analysis was conducted using the guideline of interpretative phenomenological analysis.

The study revealed that the Maldivian mothers' experience of raising children with autism consists of four distinct, but interconnected stages in their journey. These four core stages and its findings have several implications for both the clinicians as well as other significant service providers who work with children with autism and their families.

The initial stage, Stage One is characterised by the mothers' sensing of some differences in their children's development at a very young age. The mothers intuitively become aware of communicative, behavioural and social differences in their children. The process what the researcher has labelled as a process of 'maternal

intuitive diagnosis' where by the mother begins her search of attempting to get a diagnosis for what the mothers have intuitively sensed in their children. What the mothers innately believe as a significant difference in their children. The significant clinical implications here are that clinicians who come in contact with the mothers need to embrace what the mothers have sensed and are uncomfortable with. This acts as an early identifier and hence will buy time for the clinicians in helping the child as early on as possible. Early identification, intervention and treatment cannot be overemphasised in long-term disabilities.

Stage Two initially starts with a challenging process of the mothers' trying to accept the diagnosis of a disorder such as autism which has long-term implications and barriers to the normal development of their children. Here an interesting finding was that as mothers while going through the grieving process as their children are diagnosed with a lifelong disability also have to simultaneously go in search of the necessary treatment and schooling for their children. This stage has many hurdles and challenges mothers face as treatment was not readily available within the country. Hence they had become like 'warriors' in a battlefield charging against all the odds to get the help they need for their children in the hope of finding a possible cure they so desire as mothers for their children. This stage highlights the implications for the state and service providers to provide maximum support for the children, mothers and their families.

Stage Three becomes a crucial point whereby the mothers goes through an extremely emotional period which results in a deep depression. Having gone through some amount of treatment and facing the challenges that came along, this is the point at which the mothers starts realising the reality and magnitude of their children having

autism means for their children, themselves and their family. This is the point at which the mothers' finally begins the real process of acceptance of one's child having a long-term disability such as autism as one's destiny in a faith-based (Islam) positive way. From here the final and most important process of the journey begins. That is the process of which the mothers starts to undergo a process of a 'metamorphosis of self' to move forward with their children. This stage has specific clinical implications for clinicians as well as support service providers to support the mothers medically and psychologically in a culturally suitable way. Here the importance of maternal well-being cannot be overlooked for the sake of the mothers, the autistic children and their families.

Stage Four marks the most significant finding of the research. The mothers go through and complete the process of 'maternal Metamorphoses' and finally, come to accept the chronic nature of their children's condition. The mothers transform themselves, their identity, their beliefs and dreams, empathise and completely commit themselves to live the never ending journey of their autistic children with them for them. The many features and the central phenomenological meaning of raising an autistic child is embedded in this phase of the lived experience.

Considering overall findings of the research it has highlighted the important role of the mother from the very early stage of the child's development such as sensing the differences in their child, the enduring nature of the mother in searching for the treatment and the ability to even transform oneself in order to commit to her child fully. Hence the mother's role in the treatment process cannot and should not be overlooked. Thus what the researcher has chosen to name as the 'mother-therapist

model' to treatment of children with autism need to be considered in treating autistic children in a most meaningful way.

Regarding prospectus for future research, the findings of this study suggest the need for future research on the role of fathers and siblings in creating a conducive environment for therapy. Also, research can also be focused on finding the gaps between the service receivers and service providers.

The researcher hopes the findings of this study will be of use to clinicians treating children with autism or any such long-term disability. Some important implications that are of use to clinicians can be at the process of diagnosis, counselling, treating and empowering the mothers (caregivers) through their journey of raising their autistic children. In addition, the researcher hopes that other significant service providers such as the state, policy makers, educational institutions, NGOs, etc. who works with families of children with autism will embrace and incorporate the findings so that services are made more holistic and meaningful for mothers and their children with autism.

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APPENDIX

Appendix 1: Interview Protocol

Preliminary questions related to selection criteria

- What is your child's age?
- Since how long has he been since you have realized your child has a problem, is different? (How old was he/she then)

1. What is your experience of having a child with autism?

- How has the years been? (what were and are your feelings like)
- How did the others react? (I mean family/friends/strangers, etc)
- What had helped you the most? (Was it medication, therapies, etc)
- Who helped you the most? (Doctors, therapists, family, friends, etc)

2. What were the difficulties and challenges that you have encountered through the years?

- What were the difficulties associated with then? (For example were they related to services, within home, outside home, etc)
- What are the difficulties associated with now? (services, within home, outside home, etc)

3. If the choice was there what would you have hoped to happen?

- What are your difficulties now? (I mean do you have any specifics you want)
- Ideally what would you hope to be happening now? (What do you wish is available now)

KEY

- Sub questions to be used as prompts, to be used if really needed only

Note: V specific questions need to be avoided unless if needed only

Appendix 2: Consent Form – Individual interviews

Research Title: Journey through Hope towards Hope: Experiences of Maldivian Mothers Raising Children with Autism Spectrum Disorder.

PARTICIPANT CONSENT FORM AND CONFIDENTIALITY AGREEMENT:
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INDIVIDUAL INTERVIEWS

This consent form will be held for a period of five (5) years

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree not to disclose anything discussed in the interview

I agree/do not agree to the interview being audio taped

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: _____ **Date:** _____

Full Name – Printed: _____

Appendix 3: Information Sheet

Participation invited in the study of: Journey through Hope towards Hope: Experiences of Maldivian Mothers Raising Children with Autism Spectrum Disorder.

INFORMATION SHEET

Introduction:

I am Farzana Shaugee, a student undertaking a research project as a requirement for the Doctor of Philosophy degree at University Malaya, Malaysia. My supervisors are Dr. Siti Hajar Binti Abu Bakar Ah and Dr Haris Abd Wahab, Department of Social Administration and Justice, Faculty of Arts and Social Sciences, University Malaya, Malaysia.

The purpose of this study is to examine the experiences of carers of children with autism spectrum disorder in the Maldives. The study will seek an in-depth understanding of mother's journey of caring for their children with ASD. The study aims to find out the triumphs and also the difficulties and the challenges faced by the carers in the process.

Participant Recruitment

The participants in the study are main caregivers in particular mothers of children with autism spectrum disorder in the Maldives. The inclusion criteria is based the children's diagnosis and having at least had 2 years of having gone through the process after their children has been diagnosed with having the disorder. The number of participants will be between 6 to 8 carers.

No risk is much anticipated but those who may find any discomfort during the interview process have the right to discontinue and thus remove themselves from participating in the study.

Project Procedures

The data will be collected by means of indepth- interviewing. All data collected, such as notes, forms, interview tapes and computer documents will be kept confidential by the researcher and then disposed of.

Participants in the interviews will be involved in the interview process for not more than one to one and half hours duration. Some extra additional half an hour is anticipated when the researcher meets the participants to hand them (and later collect) the transcripts, for the members check approval and in case of the need to clarify some questions.

You, as a participant in this study, are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any particular question
- withdraw from the study anytime during the period of the fieldwork
- ask any questions about the study at any time during your participation
- provide information on the understanding that your name will not be used

- be given access to a summary of the project findings when it is concluded
- ask for the audio tape to be turned off at any time during the interview

Project Contacts and Ethics Review

Please feel free to contact me or any one of the supervisors listed below, if you have any questions about the project.

This project has been evaluated by peer review and judged to be low risk. The researcher named above is responsible for the ethical conduct of this research.

If you have any concerns about the conduct of this research, that you wish to raise with someone other than the researcher you are free to contact any of the supervisor below.

Researcher Contact Details

Farzana Shaugee
e-mail: fshaugee@hotmail.com
00960-7775115 (Mobile)
00960-3324226 (Home)

Supervisor Contact Details

Dr. Siti Hajar Binti Abu Bakar Ah
Head of the Department
Dept of Social Administration & Justice
Justice
Faculty of Arts and Social Sciences
University Malaya, Malaysia
e-mail: shajar@um.edu.my
0060379675624 (Malaysia)

Dr Haris Abd Wahab
Associate Professor
Dept of Social Administration &
Faculty of Arts and Social Sciences
University Malaya, Malaysia
e-mail: haris@um.edu.my
006079675601 (Malaysia)